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Community Member and Faith Leader Perspectives on the Process of Building Trusting Relationships between Communities and Researchers

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Abstract

In the first phase of this research, we conducted, audio-recorded, and transcribed seven focus groups with more than 50 English- or Spanish-speaking women of childbearing age. Qualitative analysis revealed the following themes: (1) expectation that participation would involve relationships based on trust that is built over time and impacted by cultural factors; (2) perceived characteristics of research staff that would help facilitate the development of trusting relationships; (3) perceptions about the location of the visits that may affect trust; (4) perceptions of a research study and trust for the institution conducting the study may affect trust; (5) connecting the study to larger communities, including faith communities, could affect trust and willingness to participate. In the second phase of this research, we conducted, recorded, transcribed, and analyzed interviews with leaders from diverse faith communities to explore the potential for research partnerships between researchers and faith communities. In addition to confirming themes identified in focus groups, faith leaders described an openness to research partnerships between the university and faith communities and considerations for the formation of these partnerships. Faith leaders noted the importance of finding common ground with researchers, establishing and maintaining trusting relationships, and committing to open, bidirectional communication. *Clin Trans Sci* 2014; Volume #: 1–9

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Much has been written about the importance of developing collaborative and trusting relationships with community members when conducting research in the community.^{1–5} With the inception of the NIH-funded Clinical and Translational Science Award, approximately 60 universities across the country have been able to create Community Engagement initiatives for the specific purpose of developing academic–community partnerships to enhance the translation of research findings into practice in communities. A recent report from the CTSA Consortium’s Community Engagement Key Function Committee and the CTSA Community Engagement Workshop Planning Committee⁶ strongly emphasized the need for sensitivity among researchers regarding the community members with whom they are collaborating; particularly, they emphasized the importance of researchers clarifying that they are not simply trying to recruit more participants for clinical trials, but that they are sincere about wanting to partner with community members to develop research projects that are relevant to the community and whose findings can be translated into the community. The purpose of our study was to explore the perceptions and expectations of communities, including community members and faith leaders, in regard to participating in the National Children’s Study (NCS).

Phase 1: Focus Groups with Community Members

We designed this qualitative study as part of our community engagement efforts for the Orange County Vanguard Center for the National Children’s Study. Our overarching goal was to better understand the communities that had been selected for the NCS and to develop community-specific strategies for outreach and engagement. The NCS is a multisite, observational, community-based population study designed to investigate the health and development of a nationally representative sample of children across the United States. Although the NCS was not designed

or implemented as a Community-Based Participatory Research (CBPR) project, NCS leadership indicated that there would be opportunities for adjunct studies, which we anticipated could include CBPR projects that could address community priorities. Thus, we sought to understand and engage the community in the core implementation of the core protocol and to plan for future CBPR projects that would capitalize on the infrastructure built by the NCS.

As a community-based population study, one of the great challenges to the NCS will be recruitment of a representative sample that includes minority groups previously underrepresented in pediatric research. As noted in prior research (Ross and Walsh),⁷ there has been extensive documentation of lower participation of minority adults in research, but little research examining minority participation in pediatric research. In their review of 192 studies, Ross and Walsh examined participation across several categories of pediatric studies. Their results indicated that in nontherapeutic research that includes invasive methods, White children were overrepresented and black, Hispanic, and other minority children were underrepresented. In contrast, black and Hispanic children were overrepresented in potentially stigmatizing research, and black children were overrepresented in clinical trials. Ross and Walsh concluded that further research is needed to determine reasons for these patterns of participation: “The problem may be at the stage of recruitment, enrollment, or retention, and additional studies are needed to determine the cause (p. 894).” As a priority for the NCS was the recruitment of a representative sample, in this research we sought specifically to understand perceptions and concerns among underrepresented communities before enrollment so that they could be addressed in a way that would promote representative participation.

This study was conducted in two phases. In the first phase, we conducted focus groups with women in the community to

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	Focus group participants	Faith leaders
Do you consider yourself to be Hispanic or Latino?		
Yes	28%	0%
No	72%	100%
Participant race		
White	49%	50%
African American	0%	12.5%
Asian	21%	12.5%
Iranian/other Middle Eastern	4%	25%
Pacific Islander	6%	0%
White/African American	2%	0%
White/Native American or Alaskan	2%	0%
No response/other	17%	0%
Religion		
Catholic or Episcopal	44%	25%
Evangelical Christian	31%	37.5%
Muslim	0%	25%
Buddhist	4%	0%
Jewish	2%	12.5%
Other protestant denomination	4%	0%
None	13%	0%
Gender		
Female	100%	38%
Male	0%	62%

Table 1. Participant demographics.

understand issues that may affect participation and trust. During these focus groups, participants described the potential role that faith communities could have in helping to build trust between researchers and participants; therefore, in the second phase of this research, we conducted individual interviews with faith leaders representing diverse faith communities to explore the potential for research partnerships between academics and faith communities. The second phase was particularly novel as only a few studies have addressed community-based research with faith-based communities. For example, Ammerman et al.,⁸ studied barriers and motivators to dietary change among congregants of 60 churches; a key finding of their research was that faith leaders expected university researchers to communicate, be culturally sensitive, and reciprocate to the community by sharing research results. In a literature review of health-related programs developed in faith-based organizations, DeHaven et al.⁹ noted that because of a lack of evaluation research, it was difficult to accurately assess the outcomes of such programs. Both studies pointed to the need for more research addressing the role of faith communities in health research and interventions.

Method

Participants and procedures

As part of the NCS planning phase in Orange County, California, 15 segments of the county were randomly selected for participation

(eligibility for the NCS during this pilot study was based on geographic location). The selected segments were representative of county's diversity in terms of geography, socioeconomic factors, and the race and ethnicity of residents. Because some of the segments had very similar demographic and geographic profiles, researchers determined that seven of the segments adequately represented the diversity of County for this qualitative study. Recruitment for the focus groups was conducted in neighborhoods adjacent to these seven segments. Researchers intentionally did not recruit women who lived within the NCS segments to avoid overburdening residents who could eventually be asked to participate in the NCS. However, sampling methods were intentionally designed to recruit participants who would be similar to the residents of the selected segments.

To recruit participants for this study, the Orange County Vanguard Center outreach team engaged community partners who distributed study flyers in the targeted communities. Community partners posted flyers on websites and distributed them through schools, libraries, and other community organizations. The flyers invited interested women aged 18–49 to call a research coordinator. The research coordinator described the study using an IRB-approved study information sheet, obtained verbal consent, and enrolled interested women over the telephone. All

women who enrolled over the telephone attended one of the seven focus groups. A total of 53 women participated in the seven focus groups (see *Table 1*). Educational and socioeconomic status varied widely (see Lakes et al. for further participant demographics).¹⁰

Research-trained moderators facilitated focus groups using the same focus group guide. Each group had between 7 and 11 participants. Latina moderators conducted two groups in Spanish. To begin each focus group, the moderator read the IRB-approved study information sheet and obtained verbal consent from participants. Once participants had agreed to begin the study, the moderator's assistant began recording the focus group session. Upon completion of the 90-minute group session, participants received \$35 in cash and completed a written demographic questionnaire.

Analyses

All focus groups were recorded and then transcribed. Spanish focus groups were first transcribed in Spanish and then translated into English. Analysis was based on qualitative thematic methods (King, 1998; Crabtree et al., 1999). Investigators first met to read transcripts and develop an initial coding scheme. They then independently coded the transcripts, and met again to review and discuss their codes. Agreement on codes was noted for each transcript: across the seven groups, the three investigators coded the transcripts with 95 to 99% agreement. This analysis led to the identification of themes in three broad categories: (1) informed

consent,¹⁰ (2) preferences for the return of individual results, particularly genetic results,¹¹ and (3) trust. In this manuscript, we focus on results related to trust which were not reported in prior manuscripts.

Results

(1) Participants expected that participation would involve social relationships based on trust that is built over time and described how cultural factors could impact the process of building trust.

Trust was identified as a prerequisite for participation in the NCS in all focus groups. Participants indicated that their initial reactions to invitations to join the study would be characterized by mistrust, but felt that it would be possible to build a trusting relationship over time between study staff and participants. For example, a Latina participant noted that this relationship should be established before data collection begins:

In the beginning maybe more, make the friendship. From there you make the next appointment, and from there the questions begin.

One cultural issue raised by participants involved concerns with trusting researchers when there was some risk of potential exposure for undocumented immigrants:

Maybe the compensation they are going to give isn't enough to completely convince some of the people. Especially the Latin families. Because we always have the trust if everything really is going to be for the study. There are many families all over Southern California that don't have legal documents and maybe that can motivate them in not wanting to participate....

[Second participant] Maybe they don't want to participate because they can be investigated. [Group agreement]

Participants noted that there are intergenerational differences in trust, suggesting that older generations and less acculturated individuals may be more suspicious when it came to participation in a research study.

As an Iranian, there will be a lot of questions and suspicion and hesitation unless you reach the second generation who were born and raised here. They're very familiar with this kind of study. If you reach the older generation, I think there will be barriers to even encourage them to participate in this study.

(2) Participants described characteristics of research staff that they believed would help facilitate the development of trusting relationships.

Participants indicated that trust would be impacted by perceived competence or expertise, familiarity or continuity, caring, trustworthiness, transparency, genuineness, warmth, and cultural sensitivity. In the Spanish groups in particular, the importance of a respectful and humble attitude received strong consensus. Participants in higher income, predominantly white groups strongly emphasized the importance of having nonaggressive researchers. Participants also emphasized the importance of

professional identification and reassurance that researchers had thorough "background checks." One participant also suggested that the researcher could be someone you choose:

Maybe it is something that you know you have an opportunity to choose. The person that you're dealing with, I mean potentially you're going to be dealing with this person for 21 years. Maybe, you know, like, I picked a doctor that I was going to deal with for as long as my son is alive. And, you know, that is something that you would want to do as you get a rapport with somebody and meet them all so you can decide with whom you want to deal with best.

When discussing comfort regarding allowing biological, particularly blood, samples to be collected by research personnel, participants described the importance of perceived competence or expertise. Some statements, like the following, referred to the importance of the data collector's skills in gathering samples:

If the person doing it [collecting blood] was professional. I know I've had blood drawn before and I was like, 'I really don't think you know what you're doing.' It's OK if it's me, but if it's my baby, you best know what's going on.

Some participants also wanted the data collectors to be able to describe exactly why each sample was being collected:

I think that if they [the data collectors] know what it is exactly that the blood is being used for and what tests are going to be done.

Other participants indicated that they would not need this level of information:

I'm probably a little different. It's interesting to hear all this cause I'm participating in a study right now where my blood is drawn every once in a while. I don't know what for and it doesn't really matter; I don't care. Something will come out at the end that will be beneficial to somebody and that's fine.

Statements also described the importance of having caring, sensitive research staff with similar experiences or backgrounds.

I feel like a lot of the [research staff] probably have had children so it would be more comfortable knowing that they've been through whatever I'm going through. So they're very conscientious of your time and feelings and so they know what to ask, when to ask, and how long to ask.

Some participants expressed strong opinions about the gender and age of the researcher, indicating a preference for women in their age range. For example, one participant said, "Pregnant women aren't going to want body measurements taken or blood drawn or whatever by men." In one group, a participant asked if university students would be involved in data collection, and there was strong consensus that participants would not want to be dealing directly with students, but would prefer someone with experience and a degree. Among some participants, there was the expectation that they would interact directly with the "top dogs" or "university professors," rather than students or research staff. Some participants also described wanting a "handler" who could manage difficult situations and be supportive when communicating about

sensitive topics. Some participants also stated that they would prefer someone who could manage children well and had a degree related to child psychology. Some participants also felt that trust would increase if interactions between research staff and participants were viewed as a mutual learning and interactive situation.

(3) Participants described perceptions about the location of the visits that may affect trust and willingness to participate.

Some participants suggested having study visits in places familiar to participants, using their focus group experience in a public library as an example of a comfortable environment. There was recognition that home visits provided some convenience:

I would rather do it all at once. I wouldn't have to drive anywhere! They're gonna come to my house! They come, they do it, it's done.

Although there was some recognition of the convenience of home visits, residents in diverse communities all shared concerns about home visits, particularly when it came to collecting blood samples and taking body measurements:

It's something about the idea of somebody coming into my house and taking blood feels uncomfortable. [Participant in predominantly White beachside community]

[Referencing blood draws in home visits] I imagine that the people will not be as confident as if they take the blood samples in like a clinic, clinic of their own doctor. [Spanish-speaking participant in a low-income, urban community]

Anything having to do with my body, I would rather go to a clinic... I would feel weird if somebody was to measure me and there's like no one nearby. [Asian-American participant in a highly educated community]

Some women also described having home visits as stressful because they felt that they needed to prepare their home ("*I would clean. All pregnant and trying to clean!*") and prepare snacks or drinks for the researcher if the visit is long.

(4) Participants described how perceptions of the research study and trust for the institution involved in the study may affect trust and willingness to participate.

Participants felt that perceived legitimacy could be increased via professional materials, including a well designed website. For example:

If I'm looking at a website and it doesn't have all the bells and whistles that I think it should, I wouldn't think it was reputable enough to involve myself in.

Some participants also felt that familiarity with the study logo and using multiple methods to distribute information would increase legitimacy. A participant stated:

And familiarity breeds comfort. The more I see that logo, the more my brain says it's legitimate.

Another theme that emerged from the groups was how institutional trust, in contrast with researcher or interpersonal

trust, would impact decisions to participate. Trust for the study or institution was impacted by the perceived legitimacy of the study and its sponsors.

I have issues with the government. I know it sounds, like, conspiracy driven, but I want to believe they want the best for our kids.

Cause if I saw UCI on there, I'd think, "Ok, that's a legitimate university."

(5) Participants described how connecting the study to larger communities could affect trust and willingness to participate.

Participants in all focus groups also felt that trust would be enhanced if the study had endorsements from important others, but there was a broad range in who they felt those endorsements should come from. Examples included: universities, hospitals, churches, mayors, and personal doctors. Among Latina participants, the endorsements of doctors and schools were especially important. Among Asian and Middle Eastern participants, endorsements from schools and ethnic media were mentioned as particularly important.

Participants in diverse groups described churches and places of worship as potential opportunities to build partnerships for research and conduct outreach to participants. In reference to being approached at home or on the phone to participate in research, one participant stated:

I always say, "No, I'm not interested," and I just hang up the phone. If I get the information from church, then I would think about it. At least think about it because I would trust more.

Participants gave examples of how faith communities could be involved in educating communities about research.

One thing is the temple and we have an Indian Sunday School kind of a thing where they would do cultural events and try to learn about philosophy and values, so that's another place you could go.

Statements also revealed the expectation among some that participation would be an interactive, social process where participants would interact with one another. Participants described expectations for communication between participants.

I think it'd be cool if there was a forum or something cause if women had other questions they could answer each other's questions. Of which you would also probably get a lot of other information with just women in the study talking with other women about the process and their children and all their stuff.

(6) Previous experiences increase the importance of establishing and maintaining a trusting relationship.

Participants described previous negative experiences in research, including the researcher's failure to keep appointments, rudeness, aggressiveness, and failing to provide the promised compensation. For these participants, it was especially important to have the opportunity to meet the researchers and develop a relationship before agreeing to participate in the study.

Phase 2: Individual Interviews with Faith Leaders

In the first phase of this research, community members described faith organizations as potential partners in the research process. Their suggestion was consistent with prior research indicating that establishing relationships with community organizations, such as faith communities, can help facilitate the recruitment of traditionally underrepresented minority populations.⁸ However, little is known about the perspectives of faith leaders regarding forming partnerships with health researchers. Thus, the objective of this phase of our research was to describe faith leaders' perspectives on health research, specifically the NCS, and on forming research partnerships.

Method

Participants

A researcher conducted interviews with eight leaders of different faith groups, including Jewish, Muslim, Evangelical Christian (including Korean Baptist and predominantly White, conservative evangelical), African Methodist Episcopal, and Episcopalian leaders (see *Table 1* for participant demographics). Potential participants were identified through focus group participants and other community contacts; all recruited faith leaders were from the same geographic communities as the focus group participants. Faith leaders were consented using the same procedures used with focus group participants. The interviews lasted thirty to 45 minutes, were audio-recorded, and were transcribed and analyzed using the same qualitative methods described in Phase I.

Results

(1) Although faith leaders recognized the study's potential value to society, they anticipated that eligible families may have some apprehension and concerns about participation.

All leaders interviewed felt that the NCS was an important study, citing its potential benefits to future generations as an invaluable contribution.

I do think that deep down, people want to help other people and it sounds like a phenomenal program to be able to help. And not just to cut costs of health care, but to create a healthier environment for children because that's an issue.

Another leader stated:

I think the NCS is a great, great venture.... I think it is something that is worthwhile...over the span of years, it'll benefit future generations...I can see that investing those 21 years for the 100,000 families across the country, two decades later will be something that is absolutely invaluable...

When asked about their initial reaction to hearing about the NCS, some faith leaders responded with enthusiasm about the study, while others described initially feeling apprehensive about the study. Some stated that their communities may not initially like the idea or might have concerns.

Faith leaders confirmed that trust would be a prerequisite for participation. Faith leaders believed that trust would be necessary in order for families to choose to participate; for example, one stated:

Probably apprehension, honestly. Maybe for myself, say someone were to come to my door and if someone were to ask a few questions and want to involve my family in a particular process, regardless of how long it would take, if I didn't know the person, even though I see a name on their shirt, or if they have the credentials to show or to prove where they're coming from, I think my first reaction would be apprehension, meaning, Can I trust this person?

In some communities, trust will be needed even before the initial contact, and in most communities, faith leaders felt that once researchers had established trust, specific concerns about data collection would be less of a problem.

Faith leaders confirmed that researchers needed to understand participants' perspectives and be culturally sensitive. When asked to identify potential barriers to participation for members in their communities, faith leaders identified the time commitment (including the length of the study as well as length and number of study visits), language barriers, individual insecurities, and perceived intrusiveness into participants' personal lives.

The primary issue would be the duration of time. I think most people would be able to commit to certain things for certain duration of time. Twenty-one years for the average person might seem fairly daunting. I mean, especially in our culture, we don't like to commit to things for too long, so that would definitely be a major issue.

I think there's an intrusion, certainly there's no doubt of that, but the only thing that would bother me is kind of the deep research into your personal life is threatening to people.

In addition, they noted that there would be cultural barriers to participation. A Korean pastor noted that among recent Korean immigrants, individuals may feel less invested in the local community, which may affect their willingness to invest time and energy in a study seen as beneficial to the United States.

As we're talking about probably Korean immigrant demographic, that sense of desire or ownership to want to do something for the community might be there, but... they would also have to overcome the barriers of language, culture, and their own sense of inferiority or insecurities regarding having an ongoing relationship with a person they might not be able to communicate fully with.

A Muslim leader noted that women in her community may be uncomfortable if study participation required them to have examinations conducted by a man. Several leaders noted that in immigrant and lower income communities, survival, rather than health would be the community priority.

In my community, I feel that the need now is just to be able to survive. Thinking about studies where the results are going to be, what, in 20 years? 30 years? Feed me today, and I'll think about this tomorrow.

Faith leaders confirmed that decision making and participation are social and family processes. Faith leaders described individuals' decisions to participate in the NCS as a

decision that would involve others, such as spouses, grandparents (in three generation homes), and faith leaders.

If it were something that I would really want for my family to do, I would encourage that and I would of course state all the reasons why we as a family should do this, because it would be a family venture. But I would definitely communicate what it was that I thought was beneficial and good for us to do, but if it was our family, I would put the decision-making, that final decision, at least 75% of that to be my wife.

Some also felt that participation would be enhanced if it involved social processes, such as events for participants where they would gather together and share their experiences.

(2) Faith leaders were open to research partnerships between the university and faith communities and described important considerations for the formation of these partnerships.

Partnerships with faith communities may increase participation and engagement and there exists some openness among faith leaders to partnerships with research studies. Faith leaders indicated that because individuals within faith communities trust their leaders and take religion and what they hear from their leaders seriously, if faith leaders were to support the NCS and deliver the message to their communities, individuals would be more open to participation.

...once you get the leaders or the clergy people in the community and they understand the program and they support you, they will be able to deliver the message and convince the community. Then it will be on the individual level.

Faith leaders were open to building a partnership with a research study, but most were unsure of what the relationship would look like. Although the faith leaders were often very supportive of the research, they were sensitive to the fact that engaging their congregations would require some effort on their part to explain the benefits and importance of the research.

It's not going to be something that they are – "Wow" – thrilled to do it. But in the long run, as working with the system and working with you and... serving the community, we feel the need of these kinds of research and studies... It's not a priority in their mind. You have to put it as a priority in their minds... But it's still not going to be an easy step, to be honest with you.

Therefore, although openness exists among the clergy, they all voiced the need for more detailed information about the study and their role as partners. In addition, as described in the next section, several faith leaders described factors that could facilitate partnerships despite several of them having had negative experiences in partnerships with secular organizations in the past.

Factors that can facilitate partnerships between researchers and faith communities. Faith leaders identified a number of factors, specific to the NCS that were described to them, that would help facilitate partnerships. First, all faith leaders believed that their congregations were interested in making a difference and that members had a genuine desire to help. Faith leaders also felt

that if the study's aims were consistent with their ministry strategy and would help the congregation to accomplish something to which they were already committed, this would further enhance the likelihood of a successful partnership.

I think we look at common values. What are the outcomes you are looking for? Are they mutually beneficial to us? Does it cause us to engage in any way in things that are conflicting with our beliefs?

Faith leaders also wanted to partner with studies that would have a high level of significance, and they felt this would enable them to acknowledge and publicly recognize their member's contributions to a significant effort.

For me, the issue in this survey is one of significance – meaning, is it making a difference? ... Say something was published in a national newspaper. If we had members in our congregation that were involved in this, I would use that opportunity to communicate to the entire body of the church to say that we have a couple of our members who are involved in this, and to then show from a national standpoint...this is what this survey is accomplishing. What that would communicate is... the reinforcement that their actions have significance, that they're a part of it even in a small way.

Some faith leaders described prior negative experiences when they had formed partnerships with governmental, academic, or nonprofit organizations. In one case, the leader described how the motivation for partnering seemed to be financial gain for the nonprofit. Most examples of negative experiences related to confusion regarding expectations and the actual costs of partnering as well as lack of role clarity. For example, a leader described how a partnership with a state government led to an unsustainable financial burden on the faith community because it increased personnel costs to support the functions of the partnership. Another faith leader had participated on a university research advisory board, but described how his role on the board was never made clear, leading to confusion about what the partnership meant.

Well, I have, here I'm working on this other thing [serving as a faith leader on a research center advisory committee] and there I'm a representative, one of the representatives of faith organizations, and honestly, to date, it isn't clear to me yet. When I go to the meetings that I've gone to, I always find them interesting, and I learn a lot, but in terms of the practical, actually making the connection, is not so clear.

Faith leaders were also asked to describe prior successful partnerships with groups outside of their faith and were asked to identify elements that made those partnerships successful. Leaders described how important it was to have well defined roles and responsibilities. They noted that if the burden of involvement was too great, the partnership would not succeed in spite of a high sense of altruism and wanting to help.

We are bombarded constantly. There are so many important things to be done... And you can't do everything, so then it's the 'ask' becomes the essential thing. What is it you're asking and who is doing the asking?

In addition to identifying trust as necessary for participants in the research, faith leaders also discussed trust between themselves and researchers as a prerequisite for a partnership. Leaders noted that in addition to what was being asked of them, another major consideration would be who was doing the asking. They described the importance of having a trusting relationship, or connection, with the researcher.

[In response to interviewer's question regarding how the faith leader would decide whom he'd be willing to partner with]. Do you know what the real answer is? I think, and it's probably just truly the way of the world, and that is personal contact, having some connection with somebody.

For some, this relationship would need to be formed before the start of a partnership. In reference to describing partnerships with other faith communities, one leader described the preference among some clergy to first establish a relationship before beginning to work together:

There're all kinds of things we want to do together, projects we want to work on, and they're like, 'No, we're just getting to know each other.'

For others, this relationship could be formed over time, while in the process of working with each other.

...Trust will come as something they can earn, not something that I can trust you first then go with you. They would earn the trust as they work along with you.

Honest, open communication is part of establishing the trusting relationship. Leaders stated that open and honest bi-directional communication was needed before any commitment was made, and that having access to information helped them overcome the initial barrier of trust. Some leaders described the importance of transparency during communication. In addition, they noted the importance of perceiving the study and researcher as having integrity. They indicated that it would be important that they perceive the researcher as conducting the study to benefit the community and not to fulfill self-seeking motives.

So, from a pastor's perspective, as I see our congregation, before I would want our group as a whole, as a ministry, to be connected to a group such as [the NCS] on a greater body-to-body scale, would be – is this something that is full of integrity, something that is truly seeking the greater good of the community, and is not in it for necessarily self-seeking motives?

Relationships between researchers and faith leaders would need to be maintained over time. Leaders also described how important it was to maintain a positive relationship with the researcher over time.

We're going to develop a relationship because all partnerships go through some challenging times where trust gets more challenging and lack of communication, but if there's a strong relationship involved, then you have a basis to work through it. I understand all of what you're trying to accomplish and how your plan is to go about it, and if we have a miss or a gap, our commitment is to call

each other first before we write anything or have a town meeting, or you know. Commitment to communication is probably our most critical thing.

Faith leaders describe important differences within and between faith communities that would have implications for research partnerships. First, faith leaders indicated that decisions to form partnerships would be made at different levels in the organizational structure. Although faith leaders described the importance of their initial relationship with the researcher, most described organizational structures in their faith communities that would be involved in decision making. These included boards consisting of members, and other faith leaders in higher positions within the organizational governance structure.

... it just wouldn't be the priest making that decision. I think it's a much smarter thing to go to your board and say, 'This is what had been proposed, this is who we've talked to, this is what they'd like to do, what do you think?'

They also stated that faith communities have different levels of openness to science, which will affect potential for partnerships. One leader described how some communities may not be willing to form partnerships:

It seems to me that your biggest challenge in dealing with faith communities is that faith communities are so different in terms of what they believe and what is right, what is wrong. For some communities, it's very black and white. You can do this and you can't do that. I would think that the studies that you all want to do might infringe on their beliefs and that seems to me that's your biggest challenge.

Another leader described a complementary relationship between science and religion:

I come from a community where all these people are university trained, so we have a common way of looking at the world. The way of looking at the world, for the last 100 years, is things develop. It's called evolution. I don't see that as a challenge to religion. I see science as being a way that – various sciences – how we understand the world, how things work. And religion asks a different question and gives us a direction that, 'OK, what are we supposed to do next?' Having the understanding gives you the grounding, but you need to – there are values that you need to apply in terms of how to improve things... And that's the role of religion. Science and religion work cooperatively. I like to quote [Albert Einstein] who said, 'Religion without science is blind, and science without religion is lame.' You need both.

Another leader indicated that although researchers and faith congregations might not agree when it comes to their world views, they could find some areas of commonality and focus on those.

And we won't believe everything you believe, and you won't believe everything we believe, but the area that we're working in is that overlapping circle, which I would assume it is. I wouldn't see – we don't need to change your whole circle and you don't have to change our whole other circle, right? We are just focusing on a mutual thing we agreed on...

Differences between and within faith communities. Faith leaders also noted that within their faith community, individual differences would affect willingness to participate in research studies.

The diversity within the community – because we’re coming from different countries and every country has its own culture and way of thinking.... I can be a Muslim from China or I can be a Muslim from the Middle East – yes, we have something in common, but we have our differences...

In addition, one leader noted that differences within faith denominational groups would impact individual church decisions to form partnerships.

We’re very much Evangelical... Our community center was partnering with the Catholic Church, which confuses some people, but was a great partnership.

Discussion

Study participants, both focus group participants and faith leaders, emphasized the importance of trust among researchers, participants, and communities. Participants described how trust is influenced by intergenerational and cultural differences and described characteristics of researchers that would help build trusting relationships; as prior research has noted, professionalism and expressing genuine respect for participants are viewed as positive characteristics that enhance trusting relationships.¹² Participants also believed that relationships between researchers and community organizations, such as faith groups, would help facilitate trust between researchers and participants.

The importance of trust described by participants is consistent with much prior research; however, a unique contribution of this study is the perspective of faith leaders, who confirmed the importance of trust. Our results indicated that some faith leaders are open to scientific research as well as partnering with the university to conduct and provide nonfinancial support for such studies. All faith leaders felt that the degree of openness to research partnerships varies widely within different faith communities. Faith leaders referred to previous experiences involving partnerships with organizations with differing beliefs to serve as a model to identify what can be done to build a successful relationship. They stressed the importance of having a shared and meaningful goal, clear expectations and roles, a trusting relationship, and ongoing bidirectional communication.

Faith leaders described how having a shared and meaningful goal would be an important consideration in their decision to form a research partnership. They noted that there are many meaningful causes, and when selecting causes in which to involve their congregations, they considered how consistent the effort would be with their ministry strategy. Thus, individual congregations may vary in their willingness to partner with different types of research studies, depending on characteristics of their congregations as well as their ministry priorities. For example, a faith leader whose congregation consisted of older adults described an interest in research studies of relevance to older adults; other leaders quickly saw the value in studying children’s health and responded with excitement to the NCS.

Faith leaders also noted the importance of clear expectations and roles to the development of partnerships with researchers.

They described how it would be hard to form a partnership if it is not clear what the commitment entails and what specifically is expected of them. They also described prior experiences with partnerships where the burden was so great that, in spite of their altruism and desire to help, it became impossible to continue the partnership. Therefore, researchers should be sensitive to the burden on the community (e.g., financial resources, time, and effort) of forming a research partnership.

A trusting relationship between the faith leader and researcher was described as a prerequisite to a research partnership. A central concept is the development of trust within a partnership in which each part of that partnership values and respects both science and religion, including the intersection of science and religion, in various ways. Faith leaders recognized that there would be differences of opinion between their faith communities and scientists, but believed that if they could work on a shared goal and express mutual respect for one another, it was possible to maintain a trusting relationship in spite of differences.

Ongoing, transparent, bidirectional communication was described as essential to an effective partnership. One faith leader described the importance of maintaining a commitment to directly address any differences or difficulties that may arise in the process, noting how all relationships involve working through misunderstandings. Our results also emphasize the importance of researchers taking the time to understand and learn from their research partners and their communities.

Limitations and Implications for Future Research

This study shares the limitations of many community-based qualitative studies including limited demographic and geographic representation. However, the data generated from this study yielded novel findings regarding partnerships between faith communities and researchers. These results can be applied to other community-based research investigations, including the development of quantitative studies that could address these topics in larger, more nationally representative samples. For example, two of the authors of this manuscript are involved in a collaborative, quantitative study to investigate the perspectives and experiences of academic and community partners who are engaged in translational research. The results of the study reported in this manuscript helped to inform the development of a new survey that is being administered to academic-community research partnerships.

Conclusion

Engagement with diverse communities requires targeted efforts on the researcher’s part and sensitivity to another’s perspective. Whether this perspective is because of religion or another cultural factor, researchers should seek to understand communities and individuals, demonstrating openness, sensitivity, and the understanding that building trust takes time and requires effort.

Conflict of Interest

The authors reported no conflicts of interest related to this study.

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