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Reducing health disparities: Developing a culturally relevant measure of partnership trust in community-based participatory research

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Reducing health disparities: Developing a culturally relevant measure of partnership trust in Communitybased Participatory Research and Programs.



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Outline

- Introduction
- Community-academic partnership (CU-PASOs)
- Framework
- Research Process
- Instrument
- Survey Instrument Pilot Testing
- Cross-cultural Cognitive Interview (CCCI): Process and Methods
- CCCI Results







Introduction

- Historical mistrust is a challenge for community involvement (Cook, & Jackson, 2012)
- Underlying assumptions of academic research teams about communities' level of understanding and acceptance (Lucero & Wallerstein, 2013)
- Latino communities increased mistrust in outside institutions (Martinez, Carter-Pokras, & Bohrer Brown, 2009)
- Building capacity in Latino communities as a key strategy to eliminate health disparities (Michael, Farquhar, Wiggins, & Green, 2008)

CBPR as an approach to research that can reduce historic mistrust (Granovetter, 1985)

Introduction

- Few studies to measure CBPR outcomes, such as partnership trust, were found in a lit. review (Hunter et al., 2013)
- Need of reliable and valid instruments to measure trust between practitioners and their target populations (Costa & Anderson, 2011)
- There is a need to reduce this gap (NIH, 2014)
- Community-academic partnership (CU-PASOs) for developing a culturally/linguistically relevant and bilingual instrument to measure partnership trust as an outcome of CBPR





Defining roles in partnership trust: Community-academic partnership (CU-PASOs)

Community
Health
Workers
(promotores)

Participants

Organizational partners

PASOs Staff and leaders

OUTCOME MEASURE

Trust in the partnership applied to community based programs and research

Trustor -----Trustee

Framework

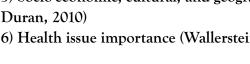
Adapted from Dietz and Den Hartog's (2006) Multidimensional Measure of Trust Model

- 1) Trustor's predisposition to trust
 - a) Propensity to trust (Costa & Anderson, 2011)
- 2) Trustee's character, motives, abilities and behaviors
 - a) Participation/cooperation/respect (Lucero, 2013)
 - b) Perceived trustworthiness (Costa & Anderson, 2011)
- 3) Quality and nature of trustee-trustor relationship
 - a) Historic collaboration: trust and mistrust (Wallerstein & Duran, 2010)
 - b) Participation in decision-making (Lucero, 2013)
 - c) Change in power relations (Lucero, 2013)
 - d) Core values for partnership (Lucero, 2013)
 - e) Cooperative behaviors (Costa & Anderson, 2011)
 - f) Monitoring behaviors (Costa & Anderson, 2011)
 - g) Length of time in partnership (Wallerstein & Duran, 2010)
- 4) Situational/organizational/institutional constraints
 - a) Community research capacity (Lucero, 2013)
 - b) Sustainability (Lucero, 2013)
 - c) Change in communication level outcomes (Lucero, 2013)
 - d) Alignment with CBPR principles (Wallerstein & Duran, 2010; Lucero, 2013)
 - f) Frequency of participation (Chandlee Miller, 2012)
 - g) Size of the group (Chandlee Miller, 2012)
 - h) Formal agreement (Wallerstein & Duran, 2010)
- 5) Socio-economic, cultural, and geography/environment (Wallerstein & Duran, 2010)
- 6) Health issue importance (Wallerstein & Duran, 2010)

7)Trust the belief **Confidence** positive **expectations**

8)Trust the decision A willingness to render oneself vulnerable

9)Trust informed actions "Risk-taking behaviors" and voluntary extra-role attitudes and behaviors



Research Process

Qualitative pilot study 2016

- Funded by the MUSC's Community Engaged Scholars Program
- Informed by theoretical framework
- Explored conceptualization and determinants of partnership trust among PASOs stakeholders

Bilingual instrument development 2017

- Back translation
- Pilot testing (4 stakeholders)
- Adaptation based on pilot testing findings

Cross-cultural
Cognitive Interviewing
2018

- IRB Approval
- Survey administration (n=21)
- Evaluating cross-cultural performance of the survey tool (21 cognitive interviews)
- Identifying issues associated with comprehension of specific terms (Willis 2001)
- Compiling informal analysis

DIMENSIONS TO BE INCLUDED IN FUTURE SURVEY Guide for internal use

1) Trustor's predisposition to trust

a) Propensity to interpersonal trust1

1) Generally speaking, would you say that most people can be trusted or that you need to be very careful in dealing with people?

Most people can be trusted.	
Need to be very careful	
3) No answer	

2) I 'd like to ask you how much you trust people from various groups. Could you tell me for each whether you trust people from this group completely, somewhat, not very much or not at all?

	Do not trust at all	Do not trust very much	Trust somewhat	Trust completely	Does not know
Your family					
Your neighborhood					
People you know personally					
People you meet for the first					
time					
People of another religion					
People of another					
nationality (only to natives)					
People of US origin (non-					
Hispanic)					
People of other nationality					
different from US or yours					
(Hispanic)					

b) Propensity to institutional trust 2

2) Please look at this card and tell me, for each item listed, how much confidence you have in them, is it a great deal, quite a lot, not very much or none at all?

9	
1	10
Ī	A
0	Ir on Family o hborhood Life
Neig	hborhood Life

In the United States					In your country of birth						
A	Quite	Not	None	Does	Does not	A	Quite	Not	None	Does	Does COMMUNI

Survey Instrument Pilot Testing

- October 23-30th, 2017
- Conducted in Greenville PASOs headquarters
- Stakeholders interviewed: staff, community participants, and volunteer CHW
- Surveys: 5

Modification of survey based on issues identified by participants

- Order of questions
- Typos
- Distinction between programs and research related tables
- Creation of two separated sections for PROGRAMS and RESEARCH





Cross-cultural Cognitive Interview script (the process)

<u>Purpose:</u> To test cross-cultural understanding, among English and Spanish speaking stakeholders, of a survey tool to assess partnership trust as an outcome of CBPR.

- Willis' protocol for identifying critical problems
- Probes developed based on the standard probes suggested by Willis
- n=21: 5 participants, 5 CHWs, 5 staff, 6 organizational partners
- Audiotaped cross-cultural cognitive interviews were transcribed into text narratives that were qualitatively analyzed using informal coding process.
- Transcription was completed in Spanish and English.
- Survey+interview on the same day with 2 exceptions (participants)
- Self-administered survey with assistance when asked (1 during pilot and 1 during fieldwork)

Interviews average duration: 50 minutes



Cross-cultural Cognitive Interview script (probes development process)

We followed the protocol proposed by Willis (2011)

- 1 First we reviewed original version of the tested question
- 2 Issues to investigate (examples)
 - a. The question contains a number of <u>technical terms</u> (vocational, rehabilitation). How well are these understood?
 - b. Question may involve a <u>long-time period</u> (<u>Recall bias</u>). How well does the respondent remember this?
 - c. Are there issues with comprehension of terms used translated from English to Spanish and viceversa.
 - d. Are there indications that they are <u>trying to please the interviewer</u>, or to just guess what is appropriate to say (i.e., Do we observe the demand effects or social desirability effects often seen in psychological experiments)?

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Informal Analysis of CCCI Results

(Willis, 2011)

- The journey from the cognitive lab to the final outcome report involves a significant degree of judgment and interpretation (interdisciplinary team analysis)
 - The application of cognitive interviewing procedures does not in itself provide precise direction in question design
 - Decisions on using quantitative data

Steps

- 1. Reviewed and documented individual interviews
- 2. Compile results across interviews grouped by stakeholders categories (4)
- 3. Analysis
 - A question-by-question review of results, with recommendations for each tested question;
 - A section listing the potential limitations of the testing and anticipated next steps, and even final decisions about question wording, when possible.

RESULTS







Example of Survey Questions	Potential Issues (Willis 2011)
4.6) PASOs has changed a research or community program because of information or an opinion I shared with them	Attitude may not exist Respondent may be unaware of the occurrence or not of some of the assumptions of this question
5.10) I've stayed involved with PASOs because I think the organization is accountable	Incomprehension of a specific term The term accountable was not clear or evident in its meaning for several respondents
3.1) For how many years have you been collaborating with PASOs?	Missing time periods/unspecified The respondent may have difficulties recalling when its involvement with the organization started
4.7) PASOs has increased efforts to allow greater involvement of community participants in decision making	Social acceptability of responses The politically correct response may be implied in the question asked

ADDRESSING ISSUES USING CCCI. Example

On the length of a collaboration and interactions

predisposition to trust Trustor's

SURVEY QUESTION

Grade your agreement with the following statements...

- I have higher trust in organizations with which I have been affiliated for longer periods of time
- I have higher trust in organizations with which I have had greater interaction

The existence of attitude

COGNITIVE INTERVIEW

What comes to mind when you think of your relationship with organizations with which you trust most?

- Several factors as key to build trust in the org.
- No answer mentioned time
- Instead, the quality of interaction or interaction itself

Many other elements arose as emerging reasons

New survey question

Which of the following ways of communication has been mostly used in your interactions with the organization

- E-mail exchange
- Phone conversation
- Face-to-face meetings

I trust the organization because the interactions I had with them have been based on

- respectful relationship
- friendly relationship
- mutual interest on the issues discussed

ADDRESSING ISSUES USING CCCI. Example

Factors influencing stakeholders decision to trust

Trust the decision

SURVEY QUESTION

{6.3} My knowledge about the mission and objectives of PASOs influences my willingness to participate in their programs

Comprehension of terms

COGNITIVE INTERVIEW

What comes to mind when you think of PASOs' mission and objectives?-

-All four types of stakeholders understood the concept.

-Offered a detailed explanation of mission and objectives.

Some staff members: confusion about concept of "participation" as used

New survey question

My knowledge about the mission and objectives of PASOs influences my willingness to work, collaborate, and participate in their programs

Conclusion

- We have strengthened the collaboration with PASOs
- We determined which of the questions asked in its original form had remained valid
- Each of the questions where issues were identified (16) had been modified or replaced by new
- CCCI pointed out misspecification or ambiguous aspects of the questions
- CCCI is a useful tool to systematically address the understanding and recall issues involved in survey design
- Next steps: Peer-reviewed publications; R01 NIH proposal



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