Use of Perceptual Mapping to Encourage Informed Decision Making on Clinical Trials in African American Cancer Patients

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Background

• Minority populations participate in clinical research at lower rates than whites, despite carrying a disproportionate load of the cancer burden. ¹,²

• Up to 20% of minority cancer patients are eligible to participate in clinical research, yet only 3-5% do.¹

• Previous studies have classified barriers to participation as protocol-related, patient-related, or physician-related.³

3. Education Network to Advance Cancer Clinical Trials (ENACCT) and Community-Campus Partnerships for Health (CCPH). (2008). Communities as Partners in Cancer Clinical Trials: Changing Research, Practice and Policy. Silver Spring, MD
Research Focus

Although barriers to participation in research among African American and other minority populations have been explored, limited research has focused on comparing the unique perceptions of those who do and do not participate in clinical trials.
Purpose

1. Use perceptual mapping techniques to determine perceived facilitators and barriers to clinical research participation in African American cancer patients.

2. Use results to guide development of a mobile application decision-aid.
Study Design

**Phase 1:** In-depth discussions with African American cancer patients who have and have not participated in clinical trials, to elicit barriers to and facilitators of participation and validate which are most critical to the patient population.

**Phase 2:** Develop and administer the perceptual mapping survey instrument to inform message foci of decision aid.

**Phase 3:** Develop a multi-media mobile application decision aid, and conduct usability testing with patients and providers.
Perceptual Mapping and Vector Modeling Methods
By measuring & mapping how they associate elements with each other.

(as distances)
Methodology – Perceptual Mapping

• Perceptual mapping uses multidimensional scaling (MDS) and message vector modeling techniques -- often used in marketing research.

• The models are three-dimensional and display how respondents perceive the relationships among a set of elements (e.g. risks & benefits). Provides insights into decision-making for diverse populations.

• Resulting map reflects how the elements are conceptualized relative to each other and relative to “Self,” an aggregate group average.
Mapping Method

- Use traditional surveys

- Respondents not required to abstractly think about how concepts are or are not related to each other, which makes the method easy to use in populations with all literacy and cognitive abilities.

- The maps provide a snapshot of the respondents’ conceptualization of the situation, and reveal the relative importance of different elements.
The Measurement Process

Mental association—judged as distance (0-10)

“0” = strongly disagree

“10” = strongly agree

How much would you agree that:

I know where to get information about clinical trials. ___

Being part of a clinical trial can give a person a sense of purpose in life. ___
Mapping Analysis

- **COGNIPLOT**, computer software developed at the RCL, is used to create the perceptual maps.

- The program converts the scaled judgments (through a scalar-products procedure) into inter-point distances used in the mapping.

- Associations among the questionnaire elements are derived from the inter-item correlations of all elements, where the absolute values of the Pearson product-moment correlations are converted to a 0-10 scale.
Resulting Map

- Don’t Trust Drug Companies
- Don’t like new tx
- Self
- Get Checkups
- Cancer Screenings
- Home Remedies
- Use Alternative Therapies
- Am Positive
- AA discriminated against
- Don’t trust research
- Drs Mislead
- Healthy Person
Vector Modeling – Creating the “Message”

• Used to “move” the person/group to the preferred location in the perceptual map by identifying the target vector (i.e. participate in a clinical trial). Push/pull like a physics model.

• By specifying the target vector and the number of concepts to be used in the final message, the software creates all possible vector resolutions, and rank orders the solutions for best fit to the target vector.

• The “best fit” solution is then evaluated for conceptual consistency and practical utility.
Application – Not the “Kitchen Sink”

• The message is designed to include and illustrate the concepts that are identified as critical for addressing the target population’s concerns, knowledge, and perceptions of risks-benefits for that particular decision.

• This procedure allows us to accurately tailor the decision aid directly to the target population’s conceptualization of the risks and/or benefits of carrying out the hoped for behavior or decision.

• Issues that are not perceived as being important are not included, thereby allowing the message to focus on only the concepts that will “move” the group toward the desired location in the conceptual space.
Vector Modeling - Example

- Self
- Best treatment
- Quality of life
- Live longer
- Dr Suggestion
- Purpose in life
- Benefits
- Free care
Phase II – Survey and Analysis
Phase II – Study Methods

Forty-one (41) English speaking African American patients at least 21 years of age were recruited from two cancer centers in Philadelphia.

Eligibility included:

- **Group 1:** Have participated in a clinical trial within the last 9 months or were willing to participate but were found to be ineligible
- **Group 2:** Have not participated in a clinical trial due to either refusing or never being offered a trial

An in-person or over-the-phone questionnaire was administered that included demographics and assessed factors that influence clinical trial knowledge, perceptions, and participation.
Demographics

Mean age: 60 (SD 12.6)
Gender: 51.2% Female
Clinical Trial Status: 36.6% had participated; 53.7% had not; 9.8% were “confused” (these 4 people were not included in the perceptual mapping analysis)
Education: 39% HS grad; 39% some college or college grad
Cancer Diagnosis: 61% diagnosed in last two years; 24% prostate, 12% breast; 12% colorectal, but 12 types represented. 75% first time.
Overall Beliefs about Medical Care

Not Participated

- Don’t Trust Drug Companies
- Don’t trust research
- Drs Mislead
- AA discriminated against
- Am Positive
- Use Alternative Therapies
- Home Remedies
- Get Checkups
- Cancer Screenings
- Healthy Person
- Don’t like new tx
Overall Beliefs about Medical Care

Participated

Get Checkups

Cancer Screenings

Self

Positive

Drs Mislead

Don’t Trust Drug Companies

Home Remedies

AA discriminated Against

Don’t trust research

Healthy Person

Don’t like new tx

Alternative Therapies
Sources of Support and Self-Efficacy

Not Participated

- Seeing Famous AAs helps me
- Trust Dr Treating Me
- Did Own Research
- Confident in decisions about Tx
- Confident in research
- Not enough time to understand diagnosis
- Someone Close Died of Cancer
- Didn’t think about it
- Importance of Treated ASAP
- Have Support
- Pastor
- Scared of dying
- Family with cancer
- Diagnosis Hit me hard
- Someone Close to Talk to
- Importance of Treated ASAP
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Sources of Support and Self-Efficacy

Participants:
- Seeing Famous AAs Helps Me
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- Someone Close with cancer
- Pastor
- Didn’t think about it
- Someone Close to Talk to
Value of Clinical Trials

Not Participated

- Value for society
- Improve My Community’s Trust of Research
- Self
  - Help other AA
  - Help others with cancer
- Help children
  - Find cure
  - Help Dr research
Value of Clinical Trials

Participated

- Help children
- Help other AA
- Help others with cancer
- Help Dr research
- Improve My Community’s Trust of Research
- Find cure
- Value for society

Self
Knowledge of Clinical Trials

Not Participated

- Heard about CTs
- Know someone on CT
- Heard about CTs
- Know where to get info
- Understand CTs

Dr. gave info
Insufficient info
Can drop out
Self
Knowledge of Clinical Trials

Participated

- Insufficient info
- Understand CT
- Can drop out
- Know where to get info
- Heard about CTs
- Know someone

Self

Dr. gave info
Reasons to Decide to Participate

Not Participated

Benefits
- Best treatment
- Quality of life
- Live longer
- Purpose in life
- Dr Suggestion

Self

Free care
Reasons to Decide to Participate

**Participated**

- Self
- Free care
- Quality of life
- Purpose in life
- Best treatment
- Live longer

Suggestion
Reasons to Not Participate
Not Participated

- Afraid
- Med care not good
- Guinea pig
- Not told info
- Researcher $$
- Health Insurance
- Dangerous
- Randomized Tx
- Doesn't improve care
- Med care not good
- Make sicker
- Too upset
- Too much time
- Not told info
- Afraid of placebo
- No one suggested
- Self
- God decides
- Beliefs
Reasons to Not Participate

Participated

- Treated like a guinea pig
- Afraid
- Health insurance
- Randomized Tx
- Too upset
- Not told info
- Guinea pig
- Afraid
- Make sicker
- Treated like #
- Researcher $$$
- Doesn't improve care
- Too much time
- Medicare not good
- Dangerous
- No one suggested
- Affraid of placebo
- God decides
- Beliefs

Beliefs

God decides
Main Messages to Emphasize in Intervention

**Six Themes**

1. I’m not sure why it is important for me to be in a clinical trial.
   
   **Theme 1 emphasize:** what CTs are and how they have informed current treatments

2. I’m not sure that clinical trials fit with my beliefs about how to treat my cancer.
   
   **Theme 2 emphasize:** CTs are another treatment option to explore, similar to home remedies.

3. I’m not sure I would want to be part of a clinical trial.
   
   **Theme 3 emphasize:** normal to be unsure about being in CT and have fears; important to talk with doctor and family about a big decision.

4. I’m not sure what a clinical trial is.
   
   **Theme 4 emphasize:** all types of things we use every day are products of research; provide basic info about CTs.

5. I’m not sure how to find information on clinical trials.
   
   **Theme 5 emphasize:** Many ways to get more information, where to get info

6. I’m not sure why I would decide to be in a clinical trial.
   
   **Theme 6 emphasize:** Higher purpose of participating in CTs; importance of making right choice for patient
Development of mychoice mobile app

What do I have to do?

There are 4 steps to completing:

Step 1: Choose from a list of clinical trials.
Step 2: Choose from a list of clinical trials.
Step 3: Choose from a list of clinical trials.
Step 4: Choose from a list of clinical trials.

How are clinical trials used in cancer treatment?

When you feel that you have cancer, your doctor talks to you about your treatment choices. Clinical trials might be an option for you, but making decisions about taking part in a clinical trial is a personal one. Clinical trials are used to treat:

- Treatment of cancer
- New drugs or treatments
- Treatment of cancer and side effects of treatment

They offer help from doctors and nurses to help their patients. In fact, the standard treatment you would receive is the result of previous clinical trials.

The chance that a clinical trial is successful depends on many factors, including how your results are compared to the standard treatment and the side effects of a clinical trial.

I'm not sure how to find information on clinical trials.

I'm not sure that clinical trials fit with my beliefs about how to treat my cancer.

Questions to Talk With Your Doctor About

Now you will be asked a series of questions that many patients have about participating in clinical trials. If you would like to talk with your doctor about a question, tap the green checkmark. If the question is not something you’d like to talk to your doctor about, tap the red x. After you’ve gone through all the questions, these are the questions to discuss with your doctor.

I want to speak with my doctor.

Now you will be asked a series of questions about your treatment options. If you would like to talk with your doctor about a question, tap the green checkmark. If the question is not something you’d like to talk to your doctor about, tap the red x. After you’ve gone through all the questions, these are the questions to discuss with your doctor.

I want to speak with my doctor.
Conclusions and Implications for Research

Perceptual mapping and vector modeling methods can elucidate message strategies to encourage clinical trial participation and clearly show how to effectively address barriers to clinical trial participation.

Research Implications: Using these methods to compare barriers in African American patients in those who have and have not participated is novel and provides a more targeted strategy to develop interventions.

Clinical Implications: Spending time discussing the clinical trial process, addressing negative perceptions of clinical trials and promoting their benefits would be more beneficial for African American patients to make an informed decision about participation, rather than interventions focusing on mistrust.
Thank You!
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