Qualitative Methods to Improve Health Disparities Outcomes

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"Health Disparity" and "Health Inequity/Inequality"

Health Disparities

"…differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific population groups." Research on disparities related socioeconomic status is also encompassed in the definition.

Health Inequity/Inequality

"…differences in health which are not only unnecessary and avoidable but are considered unfair and unjust."

NIH Strategic Plan to reduce and ultimately eliminate health disparities. October 6, 2000.

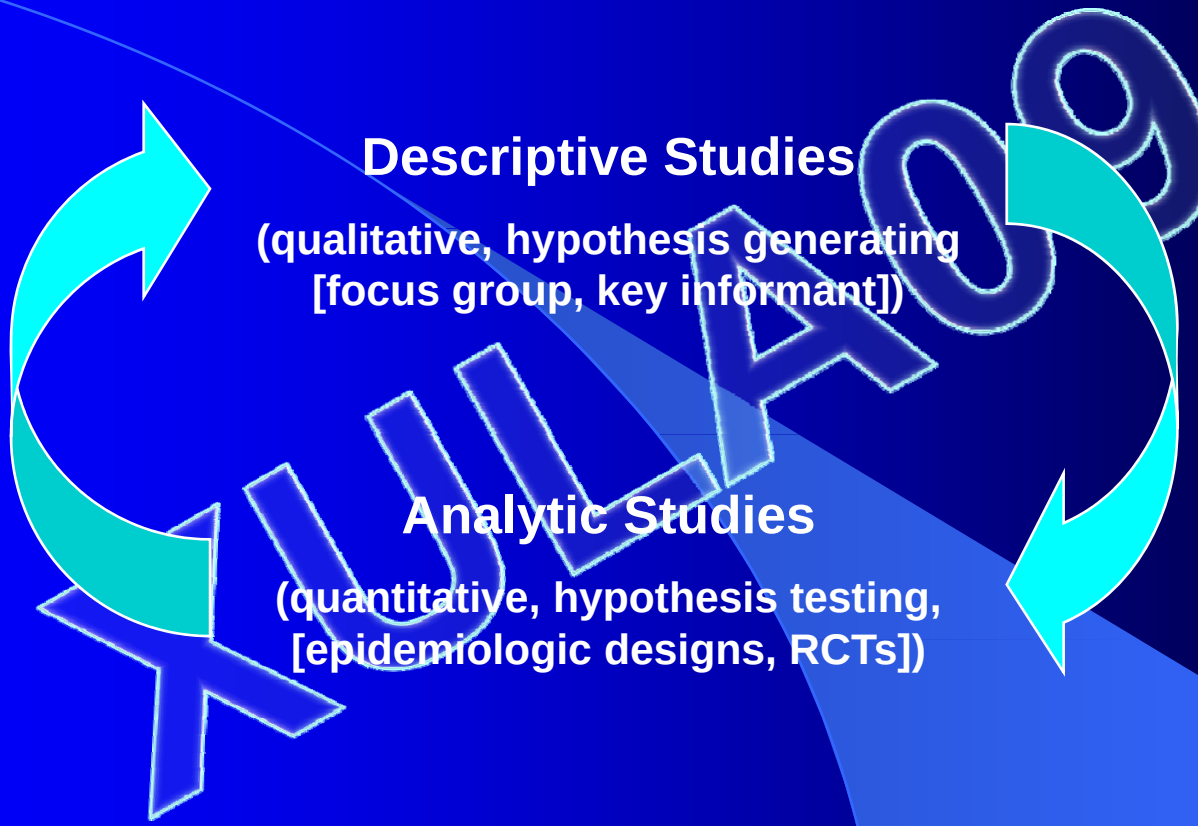
Whitehead M: "The concepts and principles of equity and health". Copenhagen: WHO/EURO; 1991.

Factors Contributing to Health Disparities

- Race/ethnicity
- Biologic and genetic determinants
- Health care determinants (access to care, health insurance, quality, bias in care delivery)
- Co-morbid conditions
- Treatment disparities – NOT based on clinical factors and evidence
- Socioeconomic status and poverty
- Cultural competence and cultural determinants
- Risk factors
- Lack of patient centered care
- Post-treatment access to and compliance with care
- Low participation/retention rates in clinical trials

MOST DISPARITIES ARE AVOIDABLE!!!

Research Designs



WHAT Is a Focus Group?

- A qualitative method
- Obtain in-depth information on concepts, perceptions and ideas of a group
- More than a question-answer interaction
- The idea is that group members discuss the topic among themselves, with guidance from the facilitator
- Discussion is usually "focused" on an area of interest
- Implementation of focus groups is an iterative process

What types of information do focus groups produce?

- Explore the depth and nuances of opinions regarding an issue
- Understand differences in perspectives
- Understand what factors influence opinions or behavior
- Test materials or products
- Test reactions to actual or proposed services
- Design a large study or understand its results
- Capture opinions and perspectives of a program's target audience

What types of information do focus groups produce?

- Learn about participants by observing their interactions
- Focus research and develop relevant research hypotheses
- Formulate appropriate questions for more structured, larger scale surveys.
- Help understand and solve unexpected problems in interventions.
- Develop appropriate messages for health education programs and later evaluate the messages for clarity.
- Explore controversial topics.

Focus Groups are NOT appropriate when you …

- Need to ask participants sensitive information
- Need statistical information about an entire population
- Are working with emotionally or politically charged groups
- Can't ensure confidentiality
- Want people to come to a consensus
- Do not have the skills to analyze the data

Advantages of focus groups

- Produce information quickly and at less cost than individual interviews.
- Excellent for obtaining information from communities with various educational backgrounds.
- In most cases, it can be easily managed by people not trained in qualitative research methods.
- Due to flexibility in questioning, may discover attitudes and opinions that might not be revealed in a survey questionnaire.
- The researcher can be present at the session which allows follow-up of responses if required.
- Usually well accepted by the community as they make use of the group discussion which is a form of communication found naturally in most communities.
- And, focus groups are good fun!

Limitations of focus groups

- Results from focus groups have limited generalizability -- can indicate a range of views and opinions, but not their distribution.
- Participants often agree with responses from fellow group members (for many different reasons) and so caution is required when interpreting the results.
- The moderator who is not well trained can easily force the participants into answering questions in a certain way.
- Focus groups have limited value in exploring complex beliefs of individuals, and as a result, in-depth interviews are a more appropriate method for this purpose
- Focus groups can paint a picture of what is socially acceptable in a community rather than what is really occurring or believed, although this problem can be limited by careful participant selection and good moderating skills.

What are the differences between Focus Groups and Surveys?

Focus Groups

- Provide depth over breadth
- Use small samples and the findings cannot be generalized
- Enable the researcher to ask a variety of questions and explore the answers as they arise
- Generate rich, complex ideas and are difficult to analyze

Surveys

- Provide breadth over depth
- Require large samples and are more readily generalized
- Are standardized but do not allow the exploration of answers in depth
- Can be relatively simple to analyze but yield less rich data

Characteristics of a Focus Group Moderator

- Adequate knowledge of subject matter
- Excellent listening skills
- Leadership skills
- Ability to build rapport with participants
- Patience and flexibility
- Observation skills
- Mental preparation

Encouraging and controlling the discussion

- Atmosphere
- Encourage discussion
- Build rapport, empathize
- Avoid being placed in the role of expert
- Control the rhythm of the meeting, but in an unobtrusive way
- Encourage involvement
- Be warm but neutral
- Ask only one question at a time

Encouraging and controlling the discussion

- Frequently repeat key phrases from the question
- Be comfortable with silence
- Pauses and prompts
- Use probes when you need more information
- Rephrase questions
- Dealing with specific individuals (i.e., dominant talkers, shy respondents)
- Observe non-verbal messages (i.e., facial expressions, body posture)

A Study to Assess African and Caribbean African American Consumers' Understanding of Issues Relating to Obesity

Background

- Obesity and overweight are major contributors to health related illnesses and death.
- There are gaps in our understanding on how African American women perceive physical activity, obesity, weight management and daily eating habits.
- Information on how African Americans perceive obesity and overweight can lay the foundation for the development of culturally sensitive weight-loss and weight-management programs.

Methods

- Used qualitative methods to conduct four focus groups among African American and Afro-Caribbean women in Baltimore City
- Focus groups were stratified by ethnicity and socioeconomic status:
  - Focus Group A: African American, low income
  - Focus Group B: African American, middle/upper income
  - Focus Group C: Afro-Caribbean, low income
  - Focus Group D: Afro-Caribbean, middle/upper income
- Key areas of discussion included:
  - Health and Well-Being
  - Health Information Seeking Behaviors
  - Eating Preferences
  - Physical Activity
  - Perceptions of Body Weight and Obesity

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Preliminary Findings (1)

- Personal challenges encountered with achieving good health related to emotional eating patterns to cope with stressors; not putting themselves first, which resulted in poor eating patterns; and poor lifestyle choices.
  - *"I also think stress has a lot to do with it too. Because when somebody is stressed, you tend to eat too much. You don't pay attention to what your eating and how much your eating. You eat chips, cookies and you just eat …."*

Preliminary Findings (2)

- Participants' perceptions of their communities suggested they did not believe their communities offered numerous options for healthy eating choices.
  - *"There is a lot of negative stimuli. If you take the strip [referring to strip malls in neighborhood], you smell grease, fries. When you go to another neighborhood, you don't have that. If you go to a white neighborhood or economic bound neighborhood, you don't have that…"*
  - *"If [I] stay in community to eat; I don't get anything healthy. There was one vegetarian restaurant but it closed. It did not stay open very long"*

Preliminary Findings (3)

- Afro-Caribbean women view any amount of body fat over the traditional weight to be considered obese, *"big, death, huge"*
  - *"I use to think obesity meant you were grossly overweight but until recently when I read Dr. Oz book, anybody 30 pounds overweight is consider obese. I never thought I was obese and now, I realize I am obese." [Afro-Caribbean woman]*
- African American women have a higher threshold for viewing one as obese. As one participant notes "*We say we are fat and fit. You can be fat and fit."*
  - *"Its all in perception. I know I am overweight but I don't consider myself an obese person. The medical community might think I am obese but I know I am over weight but I don't consider myself to be an obese person. When I think of an obese person. For example, the discovery channel-men and women laid up in bed, who can't move or breathe. That is what I think of as obese. For example, when you look at a 10 yr old child, who has to wear size 28 clothing and only 10 yrs old. That is my perception of obesity but I could be wrong." [African American woman]*

Summary

- Preliminary findings indicate women had awareness about healthy eating, diet and the importance of physical activity.
- Contextual variables related to stress management, motivation level-behavior change, time management, family and community relationships are essential for creating interventions targeted toward the needs of African American and African Caribbean women

Perceptions, Beliefs, and Informational Needs About Mental Illness Among African Americans in Baltimore City

Background

- African Americans face disparities in the recognition and treatment of mental health problems
- Personal barriers to mental health help-seeking by African Americans include perceptions of stigma and mistrust of physicians and mental health specialists
- Fear of stigma may lead to patient preferences for how mental health information is received and accessed
- There is a need to develop approaches to care that are responsive to patient values, needs, and preferences and based on a better understanding of how barriers such as stigma influence perceptions of credible mental health information sources and, in turn, the preferred modes of mental health services receipt

Purpose

The purpose of this community-based study was to understand, from a group of African American urban residents unconnected with the mental health system, what mental health information needs they perceived, what barriers they faced in accessing information and services, their views of credible information sources, and the ways in which they most wanted to receive the information.

Methods

- Used qualitative methods to conduct four focus groups among African Americans in Baltimore City
- Key areas of discussion included:
  - Things participants wanted to know about mental health/ illness
  - Preferences for how mental health information is conveyed
  - Credible sources of information
  - Barriers to receiving mental health information or services

Preferences for how mental health information is conveyed

[First response]…If I didn't know about [mental illness] and I wanted to learn about it, I want to be in a place that was very comfortable.

[Second response]…[Invited] to some place by someone I trusted …I would say my church and…I know the people that are involved.

[Third response]… Health fairs…with plenty of information and no questions asked…I should not have to answer questions about why…but someone should be on hand if maybe I have questions.

Health information and/or services are better received if conveyed in a reassuring and non-threatening manner

I was at a health fair and they were doing screening for vision, high blood pressure, and they were also doing depression screening. I was like, I'm going on the other side of the room as far away from that little booth as I can because that's where the crazy people are going to be. But I'm thinking, if groups like this [focus groups] get together and make people feel comfortable like we're not crazy, we just need somebody to talk to, to see if you're about at the edge or you can be helped…[then] some people would have went to that booth.

Preferences to foster reassurance

- *Anonymity* is maintained – no chance of the person being stigmatized by their need for mental health information.
- *Trust* that identity and the need for and/or receipt of the information (or services) remains *confidential*.
- *Familiarity* with people/setting providing assistance.
- *Supportive* people providing the information—people who are pleasant and not judgmental, impatient, or punitive about one's need for mental health information or services.

Barriers to receiving mental health information or services

- Lack of money, insurance, unfamiliar impersonal settings, unpleasantly official or authoritarian seeming personnel or processes.
- Stigma and African American collective experiences.

Stigma

Stigma emerged as a central organizing concern, undergirding many preferences and barriers. It was enough to create barriers and the intense needs for anonymity, confidentiality, and reassurance.

[Confidentiality is] huge because of the stigma. I had to think about that. It goes back to the stigma and if we could answer questions in the general practitioner's office according to a number versus your name, I'll bet that would be a flood of questions pertaining to mental illness.

Stigma

Participants discussed the following stereotypes or myths as components of stigma that creates fear of rejection, disrepute, and discrimination:

- Image that mental illness is contagious.
- People with mental illnesses are all dangerous and unpredictable.
- People with mental illness never recover, are hopeless.
- Generalized fear of mental illnesses as unknown, unpredictable.
- Shame and dishonor associated with mental illness because it is perceived to represent a personal weakness, a curse or stain, or sin.
- If one goes to a professional for mental health assistance one is likely to be labeled, pigeon-holed, and forced into treatment regardless of one's wishes.

Historical and current racism as an aspect of stigma and as a additional barrier

[First response] I tend to think some of the [non-African American] psychiatrist have preconceived ideas. The minute you enter they look at you and they've already put you in a category.

[Second response] Yes.

[Third response] And they'll ask you questions that are leading to come to that conclusion that you are this. Oh come in…I'll say this one must be homeless, drug abuse, alcoholic,

[Fourth response] Or in jail.

Historical and current racism as an aspect of stigma and as a additional barrier

[Fifth response] And they'll put you in that box and the treatment with it regardless of what you're suffering from; they've already made up their mind.

[Sixth response] I went to someone and they just couldn't believe that I hadn't been to jail. They think all black people have been to jail. You don't have a "background"? No I don't!

[Seventh response] I'll take it even to another level. For a black person to go seek professional help the professional needs to know that you're taking a stretch.

Cultural and traditional belief systems

Participants also described some African American families and communities as understanding "mental illness" through the ontological and causal lens of religion, curse, sin, and spirituality, rather than health. Although participants sometimes mentioned changes over the generations, most felt that the spiritual framework is still powerful in shaping African American communities' understanding of mental illness and emotional distress.

Cultural and traditional belief systems

Because…it [going to a mental health professional] would admit that you had a person in your family with something wrong… Socially, if a person in your family had a mental disorder it was looked upon as something went awry or for the love of superstition or revenge kind of thing. They looked upon it like it was a curse from above or somebody in their family sinned and lost his honor. So people shunned people, not just the individual but people related to them.

CONCLUSION

- Fear of stigma and racism are major barriers faced by African Americans seeking mental health/ illness information and/or services.
- Fear of stigma and racism may lead some African Americans to deny mental illness to oneself and/or others and to avoid actively seeking help.
- Some African Americans espouse culturally- and traditionally-based belief systems regarding mental health/ illness.
- Strategies and concrete steps recommended by the participants towards the design and implementation of educational interventions to address the salient barriers of stigma and racism included the need for the information and/or service to be accessible and be delivered by credible sources within a non-threatening and reassuring context.