Concept Mapping as a Tool to Engage a Community in Health Disparity Identification

Objectives: To engage a community to critically examine local health disparities.

Design: Concept mapping is a tool used to rapidly assess the variations in thinking of large stakeholder groups' about a particular topic.

Setting: Jackson, Mississippi.

Participants: Community members.

Methods: Dialog groups and community meetings were held, and participants were asked to respond to the statement, ''A specific thing that causes African Americans to get sicker and die sooner is…'' Aggregate responses were rated for importance and feasibility and then sorted into related groups. Aggregate sorts and ratings were then processed by using multidimensional scaling and hierarchical cluster analysis.

Results: There were 132 (unduplicated) reported contributors to health disparities. These responses fell into eight general clusters: economic issues, government, contextual factors, cultural factors, HIV, stress, environment, and motivation. Factors respondents felt were the most important contributors to disparities (economic factors, contextual factors, stress) did not correlate with those that they thought were most likely to be changed in society (contextual factors, government, motivation).

Conclusions: Concept mapping provided a mechanism for rapidly documenting community thinking about health disparities. This mechanism stimulated community dialog and was used as a first step toward the long-term goal of creating equal community, academic, and medical partnerships for addressing disparities. The concept mapping process stimulated critical thinking about contributors to health inequities and uncovered contextual factors previously unknown to researchers and public health planners. The process allowed for active engagement and exchange of knowledge between the community and researchers and allowed a mechanism for identifying and rectifying disconnects in knowledge within and between stakeholder groups. (*Ethn Dis.* 2008;18:77–83)

Key Words: Health Disparities, Concept Mapping, Community Dialog, Jackson, Mississippi

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INTRODUCTION

Significant health disparities exist between the African American and White populations of Mississippi across a wide variety of conditions, including diabetes, cancer, cardiovascular disease and stroke, HIV infection, and infant mortality. For example, the rate of diabetes deaths among African Americans in 2000 was 40.5 per 100,000, more than twice the rate for Whites.[1] For cancer mortality, the rate among African Americans was 255 per 100,000 compared with 212 per 100,000 for Whites. Heart disease and stroke deaths were 404.6 and 87.8 per 100,000, respectively for African Americans, both significantly higher than the rates of 323.1 and 68.7 per 100,000 observed in Whites.[2,3] All of these rates in Mississippi are higher than the United States average rates.

Health and medical agencies usually initiate, coordinate, and lead efforts to eliminate health disparities. Yet there is seldom a defined mechanism for communities to be involved in the research or planning processes around health disparities, and many communities are not technically prepared to proactively insert themselves into dialog and collaboration with these agencies. For disparity elimination strategies to be most effective, communities must play a prominent role in partnership with health and other agencies.[4–6] While the literature documents successes at engaging community groups around a specific health issue, engaging an entire community in an effective way around the less tangible issue of health inequities can be a considerable challenge for public health and medical professionals who may not have skills in community organizing and engagement.

We used concept mapping as a mechanism to initiate dialog with a community and as a way to stimulate critical thinking across stakeholders in a community around the topic of health disparities. This mechanism not only created an opportunity for community engagement on this issue but also allowed the development of a community-relevant model of disparity causality and prevention.

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Concept Mapping

During the past three decades. social researchers have developed a method called structured conceptualization, or concept mapping. The term "concept mapping" refers to any method that is used to produce a picture or map of the ideas or concepts of an individual or group. In this paper, the term "concept mapping" is used only to refer to the structured group conceptualization addressed here. This type of concept mapping is a mixed methods, participatory, group idea mapping method that integrates well-known group processes such a brainstorming[7] and unstructured sorting[8,9] with the multivariate statistical methods of multidimensional scaling[10,11] and hierarchical cluster analysis.[12,13]

Since its introduction 20 years ago,[14] this concept mapping method has been widely used in healthcare and public health contexts for a diverse range of purposes and projects. The concept mapping process involves six major steps. In the preparation step, the focus for the mapping project is identified, participants are selected, and a project schedule and logistics are determined. The generation of ideas is usually, but not necessarily,[15] accomplished through some form of brainstorming, either live or over the web, or any combination required to engage community members. The generated ideas are synthesized and, in the organization phase, participants sort them and then rate them for one or more variables of interest (eg, relative importance, feasibility). The representation of the ideas in maps is accomplished through a sequence of multivariate statistical analyses. Participants are actively involved in the interpretation of the resulting maps. In the utilization phase, the maps and associated results are used to address the purposes of the project.

METHODS

Data Collection

We applied an enhanced concept mapping process in Jackson, Missis-sippi. Concept Systems, Inc. was contracted to apply their methods and software system for concept mapping as described above. Southeastern Community Research Corporation was contracted to provide technical support for enhanced community engagement. The multi-step process used for this project is typical of concept mapping, with the addition of dialog groups to ensure effective community preparation.

The first step was to develop a focused question to prime the brainstorming process about the causes of health disparities in the community. In concept mapping, a "focus prompt" is identified that sets the stage for eliciting a brainstorming-like process among a broad range of participants. Since the topic we wanted to elicit responses on related to health disparities, we framed the focus prompt to be descriptive and used simple words in order to keep the responses focused on describing what participants thought contributed to health disparities. The question used for this process was, "A specific thing that causes African Americans to get sicker and die sooner is…"

The second critical step in the process was to identify stakeholders and members of the community. Snowball sampling was employed to identify and then recruit members of the Jackson community, including those from health services agencies, schools, community-based organizations, and neighborhood organizations and neighborhood sites to contribute toward building the framework that would, when finished, describe a community-authored picture of the issues of inequities in health.

We added community dialog groups to the standard concept mapping process in order to provide the time, space, and opportunity for those not directly involved in health work to develop basic knowledge and critical thinking about the topic. For much of the community, health disparities is not a "kitchen table" topic, thus asking them to respond to a question about health disparities without a prior opportunity to discuss the topic would create an unequal conversation between health personnel and community members. Many of these people were engaged in a dialog to begin a process of critical thinking about health disparities. The dialog sessions had three underlying objectives: 1) to introduce and contextualize the concept mapping prompt question; 2) to provide an orientation to potential community participants that included explanation of the critical role of non-academically trained experts, encouragement to think about disparities in broad terms, and dialog to assist in clarification of their concerns vis-à-vis the "expert" conceptualization of health disparities; and 3) collect data on the views of community members on health disparities in order to inform the rest of the Roadmap project. The Jackson Roadmap to Health Equity Community Partnership is a community/academic/ professional collaborative endeavor to enhance the capacity of the community of Jackson, Mississippi to participate as effective partners with the scientific, public health, and medical communities, and with social advocates and policy makers for the purpose of developing, implementing or evaluating broad-based interventions and strategies to eliminate the social determinants underlying health disparities. Ten community dialog sessions were held with >160 people participating.

In total, ≈450 people were identified through the snowball process and the community dialog groups. We asked these people to visit a website to give their responses to the prompt question, "A specific thing that causes African Americans to get sicker and die sooner is…" Participants could view the responses entered by others and could return to the site to add additional responses from September 2 through 27, 2003. Participants were also allowed to submit paper responses by mail or fax on a standard form. An onsite session

was conducted to allow community members without computer access or without facility in computer use to obtain technical assistance in participation in a facilitated group session. Twenty community respondents took advantage of this opportunity. Once the data collection period ended, the work team reviewed all of the responses generated to remove duplication, clarify some statements, and separate statements with multiple themes. This process was accomplished by the primary investigative team and the CSI contractors using a jury approach. When there was a lack of consensus about the duplication of an idea, the idea was kept to maintain what may be a unique idea.

In the next phase, a subset of participants ($n=63/130$) was instructed via email to access the internet site and rate the items in the aggregated response list. An additional group of 20 community members also contributed to the sorting and rating during an onsite session at Jackson State University on Saturday, November 15, 2003. Participants were asked to review the list and rate each item on how important they thought it was as a contributor to health disparities relative to other statements and how easy it would be to mediate the factor or condition. They used a five-point Likert rating scale (1= low, 5= high). Finally, a selected subset of the invited participants ($n=22$) was asked to review the statement list and sort the items into piles based on their conceptualization of the interrelatedness of the items. Only two restrictions on this sorting were given: any item could not be in more than one pile, and the number of piles had to be less than the number of items. This subset of participants was selected to represent a cross-section of the community members invited to participate.

The web-based system was not able to indicate how many respondents actually participated in brainstorming; however, we estimate that ≈120 invited

participants responded, based on the standard input estimation of three to four statements per participant. Four hundred and thirty-two items were generated and then synthesized to obtain 132 unduplicated responses. These responses represent factors respondents thought were contributors to health disparities. Fifty-one out of 63 invited respondents completed the rating of all factors on importance (41% of all participants), and 48 completed the rating on feasibility (39% of all participants). Of the 22 respondents invited to sort the items, all completed the activity.

Analysis

The concept mapping analysis operates on the data gathered from participants at the sorting and rating points in the process, using the numbered list of statements that are specific responses to the focus prompt. The fundamental data for a map come from the unstructured or free sort, in which each participant organizes or groups the generated statements into piles of similar ones.[8,9] Participants are free to use as few or as many piles as they think necessary to arrange the statement set meaningfully in terms of their similarity. These data are decidedly judgmental and qualitative and are reflective of each participant's view of the ideas and their relationship to each other. To use the data in the subsequent quantitative multivariate analyses, each participant's sorting result is first converted to a 0,1 co-occurrence matrix that has as many rows and columns as there are statements, where a 1 is entered into a cell if the row and column statement pair were placed by the participant in the same pile and a 0 is entered if the statements were not sorted together in a pile.[9] These matrices are then summed across all participants, yielding a similarity matrix that indicates the number of participants that sorted each pair of statements together. A high sum for an individual combination of items indi-

cates that many people sorted the items in the same grouping, while a low sum indicates that the two items were less likely to have been sorted in the same pile by respondents, thus representing low aggregate perception of conceptual interrelatedness of the items.

This summed square similarity matrix is the input for multidimensional scaling (MDS) analysis, which represents the table data as distances in Euclidean space.[10,11] In concept mapping, the MDS solution is typically restricted to two dimensions to allow for the integration of additional information from cluster and rating analyses as the "third" visual dimension of meaning. Thus, for each statement, the MDS analysis yields an x and y value. When plotted in a bivariate plot, these constitute the basic "point" or statement map form of the concept map. The MDS x and y values are the input for hierarchical cluster analysis using Ward's algorithm, which has the effect of partitioning the MDS statement map hierarchically into non-overlapping clusters.[12,13,16] Clusters arrayed in close proximity to each other have a stronger meaning relationship than those situated farther apart.

Typically the analyst facilitates the discussion of a subgroup of participants who select the number of clusters most useful for the purposes at hand. This cluster arrangement is superimposed on the point map (the cluster map), and the participant group typically names these clusters. If rating data are collected in the project, they can be averaged for all participants and for any subgroups and can be overlaid on a point or cluster concept map to identify meaningful patterns. In this project, maps were constructed spatially to represent the relationship of items as determined by the respondents. The "cluster rating" map was constructed with height of the cluster as an indicator of the rating on two indicators: importance and feasibility. One layer of height corresponds to an aggregate rating of one on a Likert

scale, and five layers correspond to an aggregate rating of five.

In addition to the point and cluster maps (with or without ratings overlaid) several graphics have proven indispensable, especially for comparing multiple patterns of ratings at either the cluster or point level. The pattern match or "ladder" graph is a bivariate comparison of the cluster average ratings that shows aggregate patterns and can be used to compare for a single variable the ratings of multiple groups or waves of measurement, or to compare multiple variables.[17] Instead of being arranged in typical x,y axis form, the two axes are set vertically side by side and joined by a separate line for each cluster that indicates average cluster rating. This arrangement makes it much easier than a bivariate plot does to detect visually whether there is overall agreement between patterns and where the patterns may specifically disagree.

Bivariate analyses were conducted between importance and feasibility of the clusters. A pattern match chart was constructed to assess the perceived mutability of the important versus less important contributors to health disparities. Finally, each item was stratified by

Quadrant	F−	F+
I+	A	B
I−	C	D,

its importance and feasibility ratings and mapped in quadrants or zones. All items fall in one of four quadrants represented by a 2×2 table: where A= I+F−, B= I+F+, C= I−F−, D= I−F+, and I+= important, I−= not important, F+= feasible, F−= not feasible. (Data not shown.)

These quadrants identify "go-zones," a structured ordering of the multiple responses ($n=132$) in a manner that suggests a prioritization of activity based on this relationship between importance of the contributor to
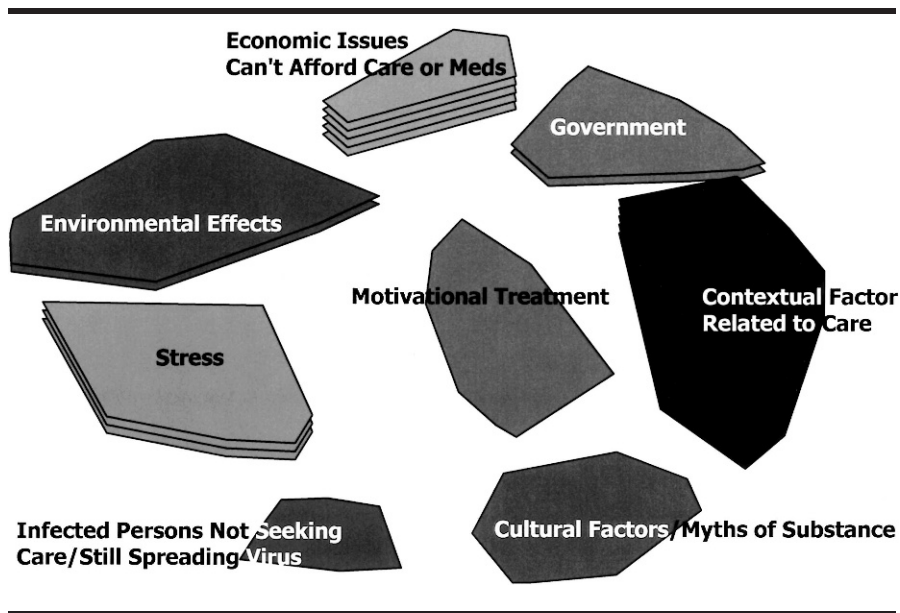

Economic Issues
Can't Afford Care or Meds

Government

Environmental Effects

Motivational Treatment

Contextual Factor
Related to Care

Stress

Infected Persons Not Seeking
Care/Still Spreading Virus

Cultural Factors/Myths of Substance

Fig 1. The final eight clusters

health disparities and the feasibility of modifying the factor.[17]

While pattern matching is especially useful for high-level pattern assessment, go-zones are particularly valuable for detailed use of the maps for planning or evaluation at the statement, or idea, level. The point and cluster concept maps, with various rating data overlaid, the pattern matches and go-zones, and accompanying detailed tabular statistical results constitute the primary analytic results that the participants subsequently interpret and utilize.

All analyses were conducted using Concept Systems version 1.751, Concept Systems, Inc.(Ithaca, New York).

RESULTS

Sample

The age of the respondents who rated the items ranged from 24 to 70 years. Most respondents (72%) had ≥16 years of education. Most respondents identified as African American (87%), and 11% as White, non Hispanic. Seventy-two percent of the respondents were women. The primary health outcomes of interest of respondents were: HIV/AIDS/sexually transmitted diseases (24%), community health (20%), women's health (13%), diabetes (9%), cancer (7%), cardiovascular disease (7%), hypertension (7%), pregnancy and infant health (4%), and substance abuse (2%). The largest proportion of respondents were community members (30%), while 15% identified themselves as scientists/researchers, 13% as advocates, 11% as social service providers, 7% as medical providers, 4% as public health practitioners, 9% as other public service, and 13% as "other".

Jackson Concept Maps

Assessment of the 132 individual items within this group of clusters suggested the items were related in eight unique clusters of items deemed to be important contributors to health disparities. These eight clusters were identified and given representative names: government, contextual factors related to care, motivational treatment, cultural factors/myths of substance, infected persons not seeking care/still spreading virus, stress, environmental effects, and economic issues/can't afford care or medicines. These eight clusters are shown in
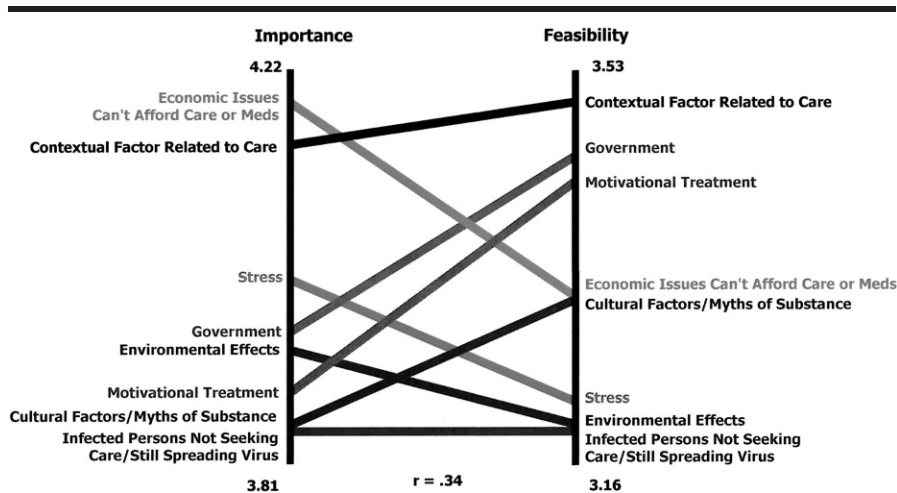
Fig 2. Bivariate pattern match for each cluster

This concept map project is a first step in a longer-term roadmapping process that will assist Jackson, Mississippi in developing a community-wide, collaborative health disparity elimination strategy

Figure 1; those that were strongest contributors have the most layers, and those considered lesser attributors have fewer layers. Figure 2 shows a list of the clusters by importance toward contributing to health disparities on the left side of the graph, and the ability to change/affect the contributor on the right side of the graph. Economic issues/can't afford care or medicines and contextual factors related to care were believed by respondents to be the most important contributors to health disparities. Stress, government, and environmental effects were the next most important contributors. Motivational treatment, cultural factors/myths of substance, and infected persons not seeking care/still spreading virus were seen as less important contributors when compared to the other factors.

In contrast, respondents felt that infected persons not seeking care/still spreading virus, environmental effects, and stress were the least likely to be amenable to change, and contextual factors related to care and government were the most amenable to change, followed by motivational treatment and cultural factors/myths of substance. Bivariate pattern matches between feasibility and importance of each cluster indicates relatively low correlation (r=.34) between the perceived importance of a group of contributors to

health disparities and the ability to change the factors (Figure 2).

Using the go-zone quadrants for each cluster, contributors were identified by their importance and feasibility. There were 38 contributors that were seen as both important and feasible to change and 32 important causal factors that were deemed not easy to change. Each cluster typically had an even amount of contributors in each go-zone.

DISCUSSION

Most efforts to address disparities occur at the institutional level and are not inclusive of the voices of the communities most affected. In this project, the residents of Jackson were given an opportunity to participate in the conversation about health disparities in their community. Understanding how the community conceptualizes health inequities is a critical first step toward defining solutions to eliminate these disparities, particularly if public health and medical professionals expect community involvement in implementing the solutions. This concept map project is a first step in a longer-term roadmapping process that will assist Jackson, Mississippi in developing a community-wide, collaborative health disparity elimination strategy.

In theory, the strengths of the concept mapping approach lie in its participatory nature, its ability to include a diverse set of participants, its ability to document the state of scientific thinking on a particular topic, and the stimulation toward deeper thinking about health disparities by participants. The process represents a true democratic process in which the minority view remains a part of the discussion and never gets filtered out or overshadowed by the majority view. However, if a representative cross-section of the community is not captured or the response rates are low, the possibility of capturing the universe of ideas and responses is diminished.

Utilizing concept mapping as a research tool in Jackson was highly effective to the initiation of the process to eliminate health disparities in the community. Concept mapping encouraged community members to lend their voice to the research by providing their thoughts on health disparities. The results showed eight main causal areas for health disparities and have provided numerous opportunities to move toward creating a roadmap, or action plan. Within each causal area are specific items representing the relevant social context in Jackson. Using both the actual maps and resulting go-zone information has allowed for the project to begin discussions on setting priorities based on what is important to this community.

Each of the contributing items from the clusters was judged regarding its importance in eliminating health disparities as well as its feasibility for undertaking. The information was then put into four categories: important and feasible to change, unimportant and difficult to change, unimportant and easy to change, and important yet difficult to change. How the contributors fall into the categories can affect how the community should begin planning to eliminate health disparities. Those contributors that are considered both important and feasible must be considered in any strategy or action plans created. Similarly, those contributing factors that are considered important but not easy to change should also be included. Although difficult to change and requiring a lot of hard work, this set of factors is seen as critically important as a causal factor in health disparities. Many scientists, program planners, and community members discard these activities from funding and research because they are apparently intractable, potentially expensive, and perhaps outside of the domain of the public health agency. Nevertheless, addressing these may spell the difference in success or failure in eliminating health disparities. Those that were not important, which include 29 contributors that were easy to change and 32 items that were seen to be difficult to change, should be reassessed as components of a community plan to eliminate disparities.

A think-tank should be developed, with more resources from federal, state, and local agencies, to develop strategies to increase the feasibility of addressing the relevant factors. The stakeholders in a community must recognize and commit to the fact that such a process would necessarily be a long-term process, would require collaboration with entities outside of public health, and may be expensive and require intra-institutional and community changes. However, knowing where the challenges will be in the future can assist with proper planning and can result in positive changes for the community. While these may create more challenges in order to see long-term effects, they cannot be ignored simply because they are difficult to address.

Since the creation of the maps, continued formal and informal dialog on health disparities has taken place with the community. We estimate that >500 people in the community have taken part in some aspect of this process and have become familiar and knowledgeable with the issue of health disparities. A community-wide conference was held to display and discuss the maps, which was integral, as it is important to share results of research with participants in order to keep them actively engaged in the process. A community steering committee was formed from a diverse group of 30 community members. They meet bimonthly and have assumed an active role in defining action projects to address health inequities. They were recently funded with a major grant to implement community interventions to eliminate health disparities.

A scientific roadmap can be developed with the concept mapping results as a starting point. Roadmaps can be used to assess the relevance of current activities, define how to modify scientific agendas, set funding decisions and priorities, and facilitate the elimination of health disparities. Further, it can bring awareness to and correct any misconceptions local professionals think about health disparity causality and community priorities for reduction of disparities and inequities. From here, a more unified, consistent scientific approach for studying and addressing health disparities can be developed, promising a stronger synergistic effect in the community.

This concept mapping process allowed for the emergence of a basic conceptual model for health disparity causation and for strategic planning to address these contributors to eliminate disparities. This model provides a research framework for testing putative relationships between factors that are important to community stakeholders and health disparities, and from this, a strategic plan can be designed and implemented. Through this roadmap project, Jackson can potentially become a ''model'' community for synergistic disparity elimination in the United States.

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