GRANT MAKERS IN HEALTH

Advancing Health Equity through Digital Storytelling
September 30, 2014 2:00 Eastern

Jeroan Allison, University of Massachusetts Medical School

Jesse Beason, Northwest Health Foundation

Scott Cook, Finding Answers: Disparities Research for Change

Abbie Zahler, International Community Health Services

International Community Health Services: Mapping Our Voices for Equity

Grantmakers in Health Webinar

September 30, 2014

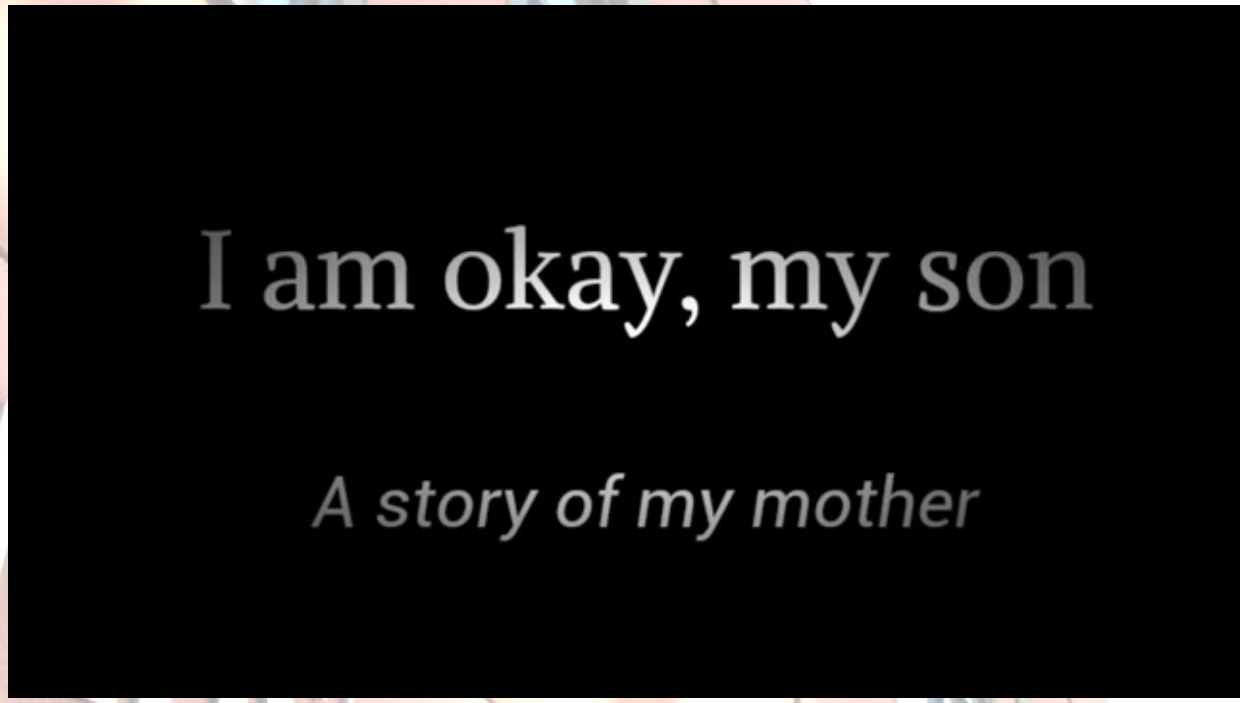
Healthy People, Stronger Families, Vibrant Communities

International Community Health Services (ICHS) provides culturally and linguistically appropriate health services to improve the health of Asian Pacific Islanders and the broader community.

Jee's Story

- 65-70% of all visits are interpreted
- Serve patients in over 50 languages every year

Jee's Story



http://www.mappingvoices.org/story/video/i-am-okay-my-son

MOVE

Mapping Our Voices for Equity

Maps and stories to promote healthy communities in Washington State

Why Digital Storytelling?

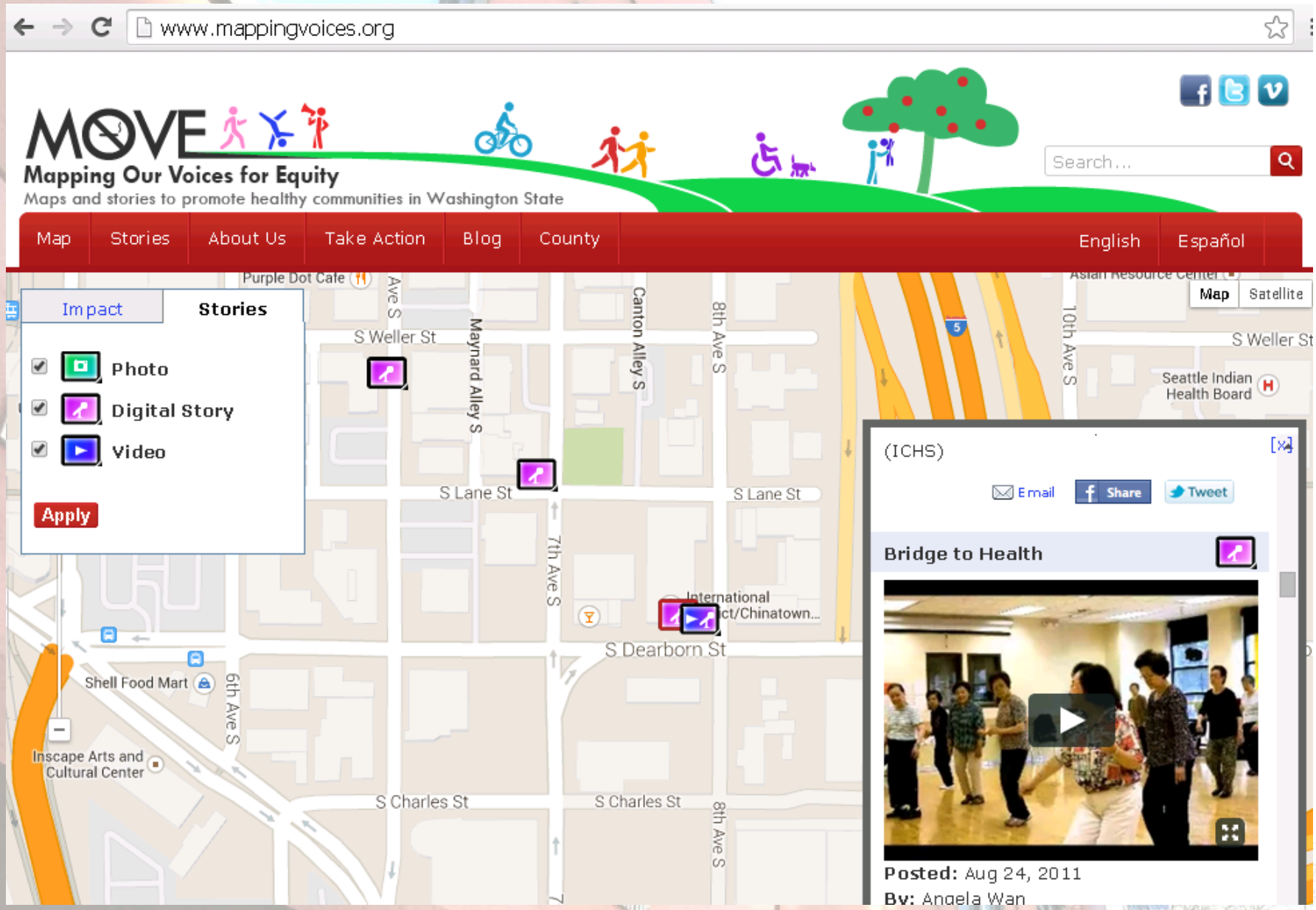
www.mappingvoices.org

Story Gathering and Partnerships

- Community Advocates:
  - Trusted in community
  - Bridge between organization and community
- Empower communities to tell their stories
- Leverage other organizational partnerships for space, equipment, tools

Angela's Story:

[Bridge to Health]


www.mappingvoices.org
MOVE
Mapping Our Voices for Equity
Maps and stories to promote healthy communities in Washington State
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Impact
Stories
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Digital Story
Video
Apply
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Satellite
Purple Dot Cafe
S Weller St
Maynard Alley S
Canton Alley S
8th Ave S
10th Ave S
Seattle Indian Health Board
S Lane St
7th Ave S
International
S Dearborn St
Shell Food Mart
6th Ave S
Inscape Arts and Cultural Center
S Charles St
(ICHS)
Email
Share
Tweet
Bridge to Health
Posted: Aug 24, 2011
By: Angela Wan

Why a Map?

- Tool to illustrate inequity in our communities
- Angela's story: neighborhood with least amount of green space per capita in the city
- Location is important when we are talking about the community center as a hub for interaction and activity

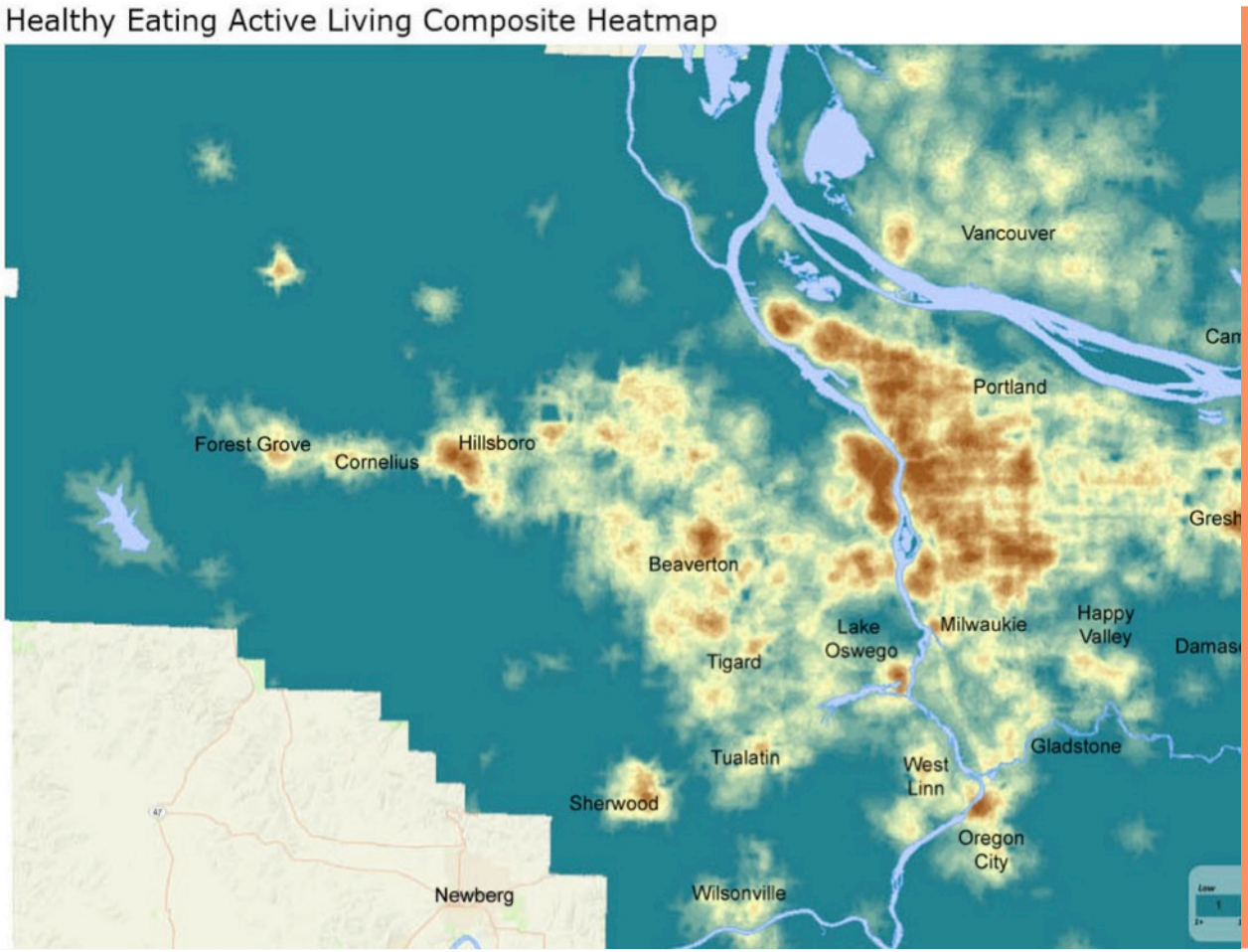
Current Projects

- Stories now include health education messages: diabetes management, mammogram access, health care access
- Created an infrastructure at ICHS to keep storytelling alive
- Creating tools to make sharing easier

International District Community Kitchen

NWHF

NORTHWEST HEALTH FOUNDATION



REGIONAL EQUITY ATLAS

A tool to understand how well different neighborhoods and populations across the region are able to access essential resources & opportunities.

Web-based mapping tool

Interpretive website

Outreach & education

REGIONAL EQUITY ATLAS

equityatlas.org

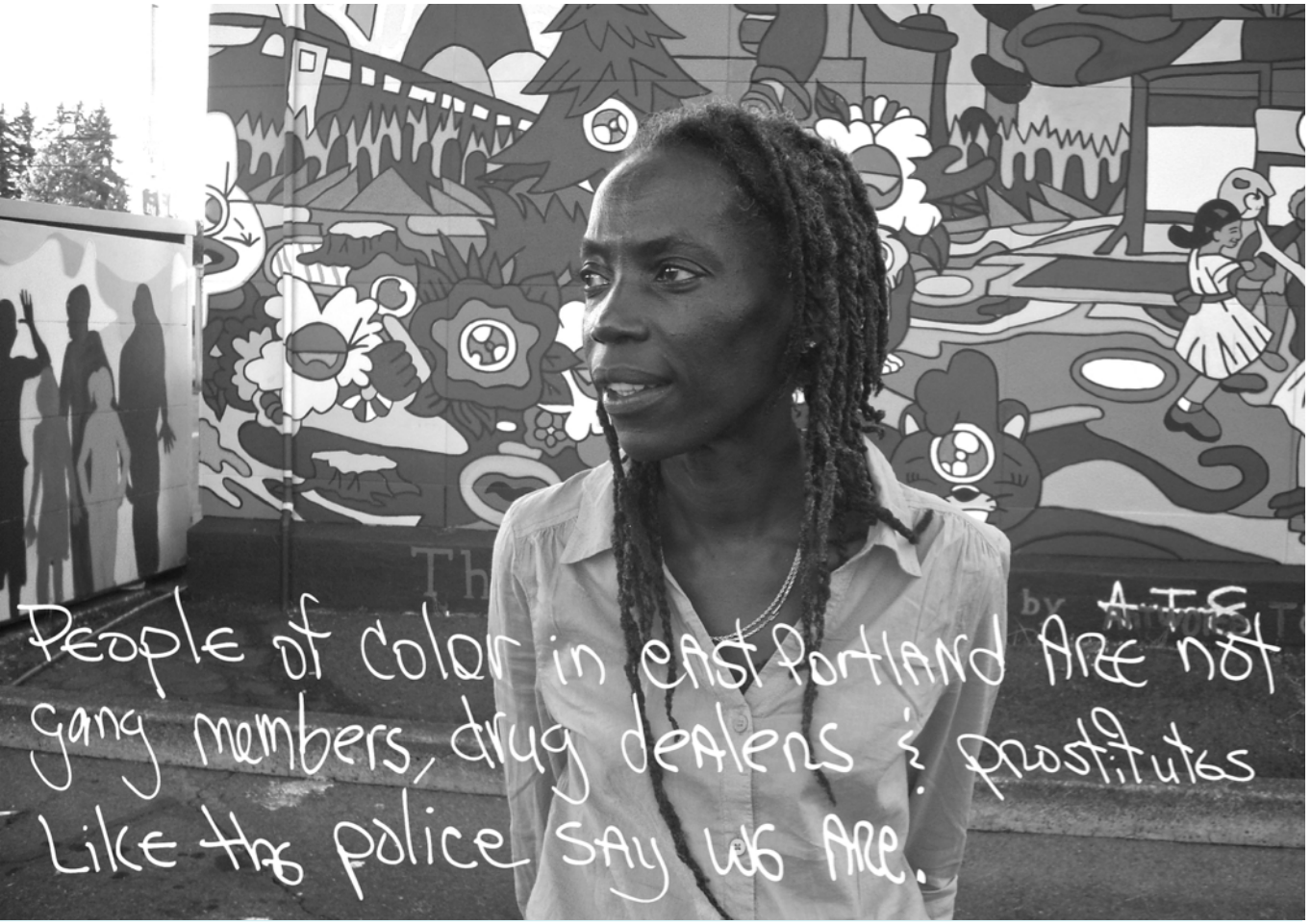
CREATING CHANGE

“BEHIND EVERY MAP ARE REAL PEOPLE WHO ARE LIVING WITH DISPARITIES EVERY DAY.”

NWHF

NORTHWEST HEALTH FOUNDATION

EQUITY STORIES PROJECT



NWHF

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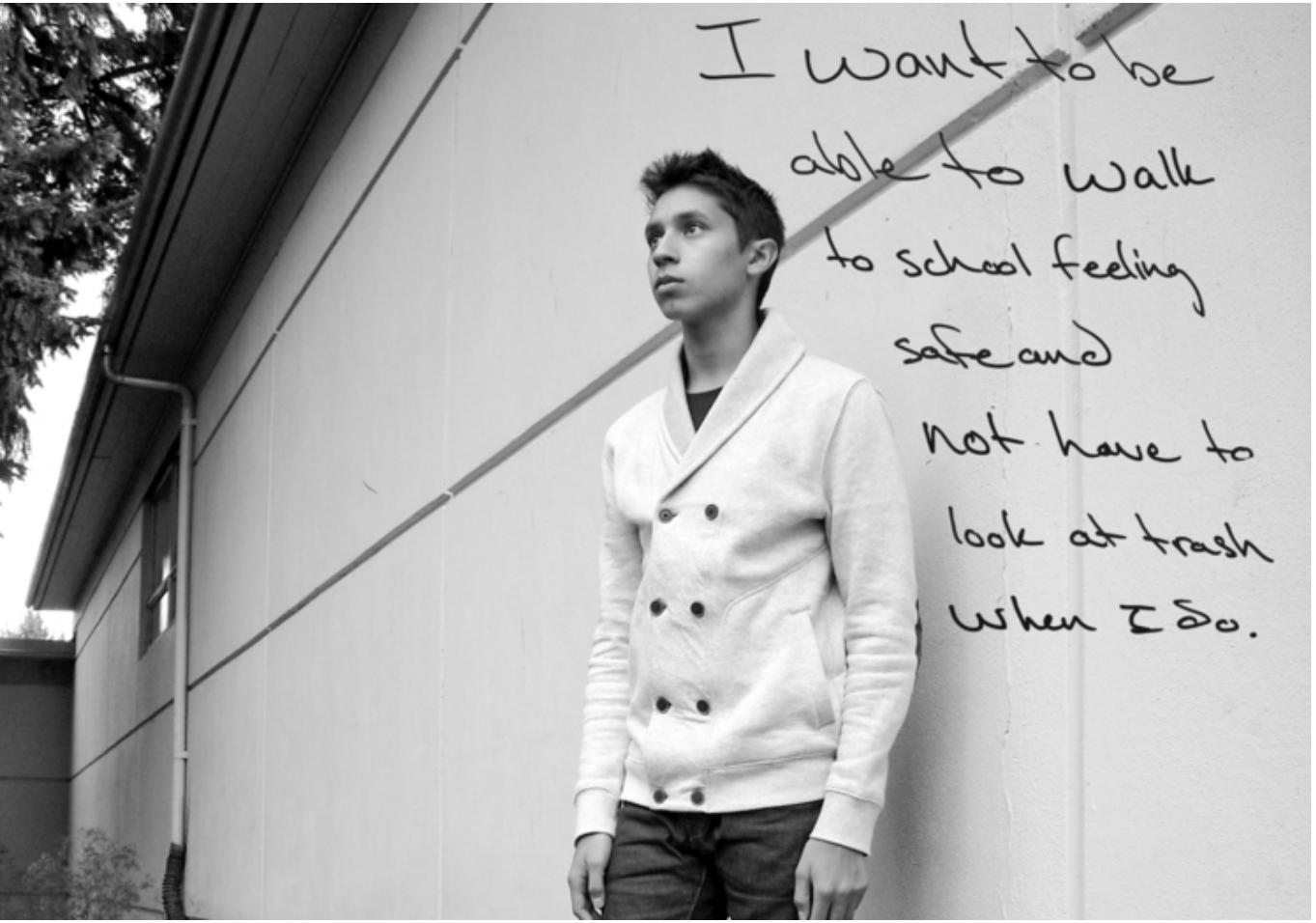
http://clfequitystories.squarespace.com/cat



NWHF

NORTHWEST HEALTH
FOUNDATION

Advancing Health Equity Through Digital Storytelling

Finding Answers: Disparities Research for Change

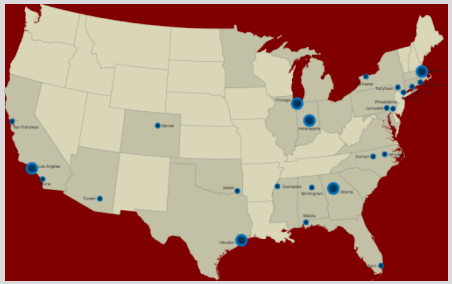
Scott Cook, Ph.D.

September 30, 2014

Robert Wood Johnson Foundation

Finding Answers is a national program of the Robert Wood Johnson Foundation with direction and technical assistance provided by the University of Chicago

National Grantee Program

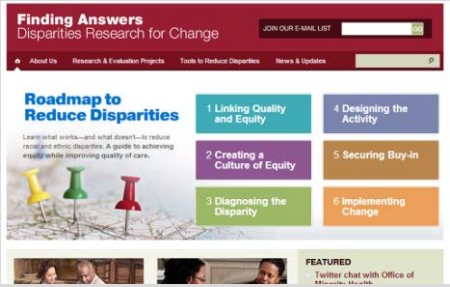


- Test innovative programs
- 33 grantees nationally
- Rigorous evaluation

Systematic Reviews

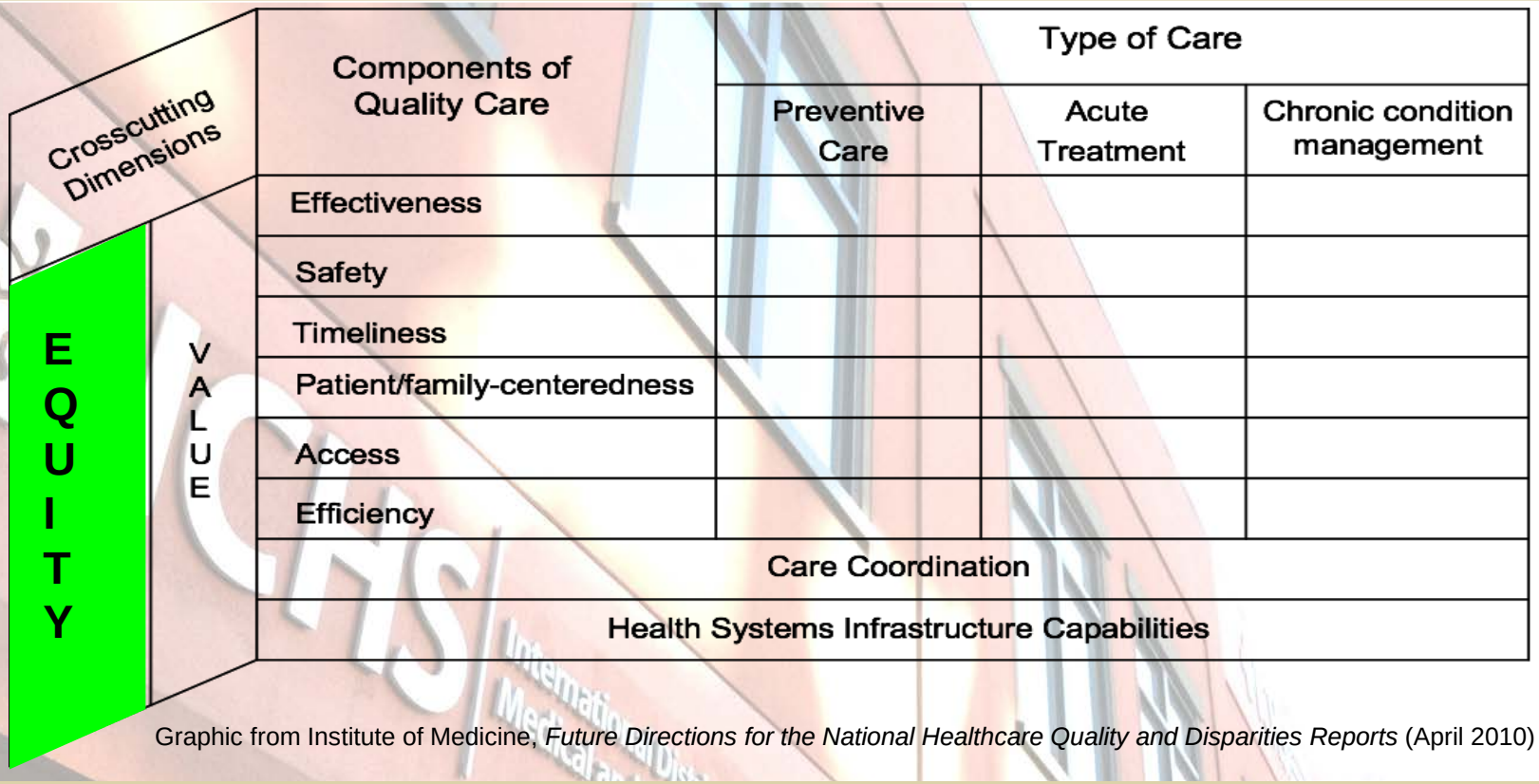
- 11 systematic reviews
- Cross-cutting themes
- Searchable database

Technical Assistance



- Roadmap to Reduce Disparities
- Aligning Forces for Quality
- Resource and implementation guides

IOM Quality Framework



Components of Quality Care	Type of Care		
	Preventive Care	Acute Treatment	Chronic condition management
Effectiveness			
Safety			
Timeliness			
Patient/family-centeredness			
Access			
Efficiency			
Care Coordination			
Health Systems Infrastructure Capabilities			

Graphic from Institute of Medicine, *Future Directions for the National Healthcare Quality and Disparities Reports* (April 2010)

A Roadmap to Reduce Disparities

Chin MH, Clarke AR, Nocon RS, Casey AA, Goddu AP, Keesecker NM, Cook SC. A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. J Gen Intern Med 2012; 27:992-1000.

www.solvingdisparities.org

Storytelling:

A Powerful and Culturally Sensitive Approach for Promoting Health Equity

Jeroan J. Allison, MD MS

September 30, 2014

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Storytelling…

- Taps into a wellspring of wisdom at the community level;
- Focuses on what's right to correct what's wrong;
- Resonates with our basic humanity; and
- Is adaptable to many different populations, health conditions, and settings.

GRANT MAKERS IN HEALTH

Culturally Responsive Health Promotion in Puerto Rican Communities: A Structuralist Approach

María Idalí Torres, PhD, MSPH
David X. Marquez, PhD
Elena T. Carbone, DrPH, RD, LDN
Jeanne-Marie R. Stacciarini, PhD, RN
Jennifer W. Foster, PhD, CNM

This literature review discusses the value of the structuralist approach as an integrated theoretical and methodological framework for participatory cultural assessments designed to capture the cultural dynamics of those affected by health disparities. Drawing from principles of the Lévi-Straussian strand of structural anthropology found in contemporary cultural studies, and using the Puerto Rican cultural experience as an example, the authors present the distinction between deep and surface structures of cultural knowledge and meaning and highlight information-processing and behavioral systems influenced by the complexity of cognitive and social representations of cultural structures. To understand and address the deeply rooted web of ideology, norms, and practices that influence health decision making and behavioral responses, the authors show the need for ethnographic narrative inquiry beyond surface manifestations of culture. Finally, the authors discuss the implications of the structuralist approach for culturally responsive health education and other health promotion interventions.

Keywords: *cultural structures; cultural assessments; Puerto Ricans; community health assessment; health disparity; structural anthropology*

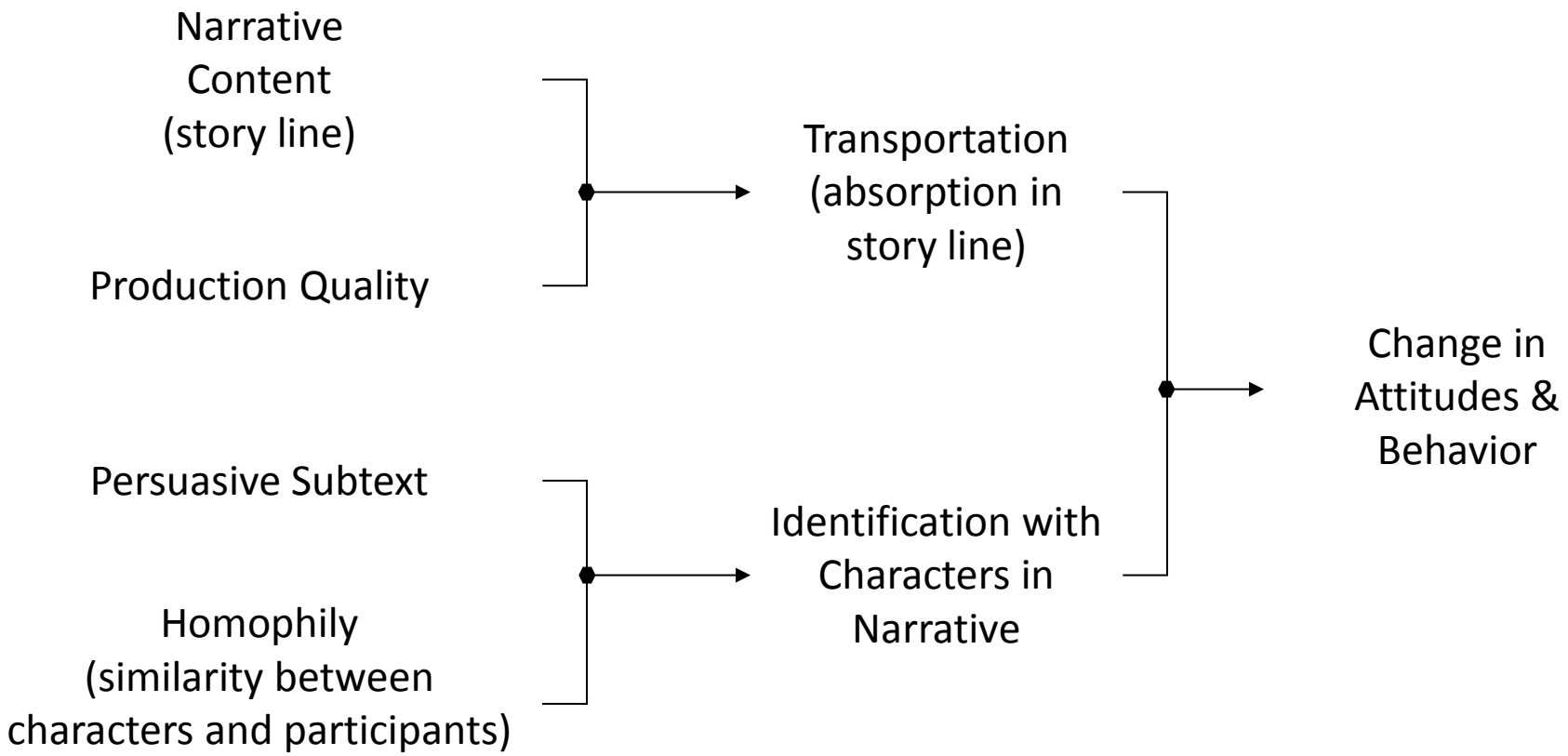
Health Promotion Practice
April 2008 Vol. 9, No. 2, 149-158
DOI: 10.1177/1524839907307675

To eliminate racial and ethnic health disparities, health promotion and health education interventions must be culturally responsive. The complexity of cultural systems and how they influence decision making and behaviors have been analyzed by some health promoters and educators in terms of the dualistic concept of deep and surface structures (Freimuth & Quinn, 2004; Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999; Resnicow, Braithwaite, Dilorio, & Glanz, 2002). Surface structures refer to visible cultural expressions such as speech patterns, social interactions, and symbols, whereas deep structures refer to systems of beliefs, perceptions, and other cognitive templates underlying behavioral patterns. This analysis suggests that the focus of health promotion and health education needs to address the complex elements of deep cultural consciousness that affect people's choices. Though not acknowledged in these analyses, this distinction between deep and surface structures is largely associated with the strand of structural anthropology practiced by Lévi-Strauss (1963) in studying indigenous concepts of healing, illness, kinship, and laws in the Americas and Africa. Used as both theoretical framework and methodological approach, this structuralist approach assumed a universal human need for systematically ordering received information and storing it at the deepest levels of unconsciousness (deep structure). This template of information, in turn, surfaces as cognitions or manifestations of preconstituted frames of reference to which people's actions conform (Manning & Cullum-Swan, 1994).

New generations of structuralists in the field of cultural studies have distanced themselves from Lévi-Strauss's (1963) static and deterministic definition of deep structure. Nonetheless, they have adopted two of his main ideas: that structures for specific actions and meanings are embedded in the relationships among

Torres, M. Health Promot Pract. 2008; 9(2):149-58.

Why tell stories?



Slater M. *Communication Theory. 2002; 12 (1): 173-191.*
Gerrig, RJ. Psychological Science. 1991; 2: 3367-340.

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The Alabama Collaborative for Cardiovascular Equality

Funded by the National Heart Lung and Blood Institute (U01 HL079171-01)

GRANT MAKERS IN HEALTH

Reported Racial Discrimination, Trust in Physicians, and Medication Adherence Among Inner-City African Americans With Hypertension

Yendelela L. Cuffee, PhD, MPH, J. Lee Hargraves, PhD, Milagros Rosal, PhD, Becky A. Briesacher, PhD, Antoinette Schoenthaler, EdD, MA, Sharina Person, PhD, Sandral Hullett, MD, MPH, and Jeroan Allison, MD, MS

Objectives. We sought to determine if reported racial discrimination was associated with medication nonadherence among African Americans with hypertension and if distrust of physicians was a contributing factor.

Methods. Data were obtained from the TRUST project conducted in Birmingham, Alabama, 2006 to 2008. All participants were African Americans diagnosed with hypertension and receiving care at an inner city, safety net setting. Three categories of increasing adherence were defined based on the Morisky Medication Adherence Scale. Trust in physicians was measured with the Hall General Trust Scale, and discrimination was measured with the Experiences of Discrimination Scale. Associations were quantified by ordinal logistic regression, adjusting for gender, age, education, and income.

Results. The analytic sample consisted of 227 African American men and 553 African American women, with a mean age of 53.7 ±9.9 years. Mean discrimination scores decreased monotonically across increasing category of medication adherence (4.1, 3.6, 2.9; $P = .025$), though the opposite was found for trust scores (36.5, 38.5, 40.8; $P < .001$). Trust mediated 39% (95% confidence interval = 17%, 100%) of the association between discrimination and medication adherence.

Conclusions. Within our sample of inner city African Americans with hypertension, racial discrimination was associated with lower medication adherence, and this association was partially mediated by trust in physicians. Patient, physician and system approaches to increase "earned" trust may enhance existing interventions for promoting medication adherence. (*Am J Public Health.* 2013;103:e55-e62. doi:10.2105/AJPH.2013.301554)

Hypertension is a leading cause of cardiovascular morbidity and mortality for African Americans.[1] Compared with other populations, African Americans are more likely to be diagnosed with hypertension, more likely to have untreated hypertension, and more likely to suffer adverse clinical consequences from uncontrolled hypertension, including myocardial infarction, heart failure, and chronic kidney disease.[2] Within the United States, the prevalence of hypertension is 45.7% among African American women and 43.0% among African American men, compared with 31.3% among White women and 33.9% among White men.[2] According to the National Health and Nutrition Examination Survey (NHANES), approximately 33% of Whites diagnosed with hypertension have controlled hypertension compared with 28% of African Americans.[3]

Several common factors contribute to poor hypertension control regardless of race or ethnicity. Although lifestyle changes such as sodium reduction, exercise, and weight loss are important in achieving hypertension control, most patients with stage II hypertension (defined as systolic blood pressure >160 mmHg or diastolic blood pressure >100 mmHg) require at least 1 medication.[2] Approximately half of the 2 billion prescriptions filled each year are taken incorrectly or not taken at all.[4] The inability to afford medications accounts for approximately 40% of the nonadherence found in the general population.[5–8] Nonetheless, the existing evidence has shown that when patients are provided access to medication at a reduced cost or at no cost at all, many patients continue to be nonadherent.[9]

Although medication adherence may be particularly low among patients with hypertension, the existing literature suggests that these differences cannot simply be attributed to socioeconomic status (SES).[10,11] Low adherence has likewise been documented to be a critical problem regardless of race or ethnicity.[12] Nonetheless, lack of adherence holds particular relevance for African Americans with hypertension because of the prevalence of cardiovascular disease and the levels of morbidity and mortality within this population.

Psychological and social factors, such as health literacy, cultural beliefs, and attitudes toward health care and the health care system, may be critically important determinants of hypertension disparities.[13,14] Discrimination based on race or ethnicity is also a powerful social force that affects both health and health behaviors. For example, racial discrimination has been linked to low birth-weight, breast cancer, stress or anxiety disorder, and poor health status.[15,16] A study of African American college students found that viewing film clips depicting acts of racism increased cardiovascular reactivity.[17] In addition to the immediate cardiovascular effects of discrimination, several studies suggest that chronic exposure to discrimination increases the risk of having uncontrolled blood pressure, although findings are mixed.[18]

The physiological response to discrimination is well documented. Stressful experiences, such as experiencing discrimination, stimulate the release of cortisol and catecholamines through the activation of the autonomic nervous system. Consistent activation of the autonomic

Cuffee, YL. Am J Public Health. 2013; 103(11):e55-62.

CSI: Birmingham

A Culturally Sensitive Intervention for Blood Pressure Control with Storytelling DVDs

Finding Answers:
Disparities Research for Change

Robert Wood Johnson Foundation

TIME

The New York Times

Ann Intern Med. 2011;154:77-84.

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CSI Birmingham Team

CSI: Birmingham

Specific Aims

- Develop interactive, testimonial-based multi-media intervention to improve HTN control
  - Medication adherence
  - Doctor-patient communication
  - Healthful life styles
- Evaluate intervention in RCT
- Develop dissemination approach

CSI: Birmingham

Intervention Development

- Story Development Groups
  - Develop semi-structured interview based on conceptual models
  - 50 TRUST patients
- Selected 13 “stars” from focus groups to tell their story
- Analyzed stories
  - Decomposed into story units
  - Each unit rated by three independent reviewers
    - Strength
    - Clarity
- Produce and iteratively refined video

Intervention Main Components

- Narrative communication
- Content and delivery by Cooper Green patients
- Health message domains
  - Stories of HTN as the silent killer
  - Stories about overcoming barriers to HTN control
    - Medication adherence
    - Diet & exercise
    - Cooked versus raw salt
  - Stories about improving doctor-patient communication
    - Fear of experimentation
    - Experiences of discrimination and lack of empowerment

Learn More Sections

- Complement patient stories
- Topics
  - What is hypertension
  - Hot to talk to your doctor
  - How to avoid hidden sodium
  - How to exercise


Main Menu
Deidre
Herman
Julia
CSI
Birmingham
DVD
Help
Learn More

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Annals of Internal Medicine | ORIGINAL RESEARCH

Culturally Appropriate Storytelling to Improve Blood Pressure

A Randomized Trial

Thomas K. Houston, MD, MPH; Jeroan J. Allison, MD, MSc; Marc Sussman, MHA; Wendy Horn, PhD; Cheryl L. Holt, PhD; John Trobaugh, MFA; Maribel Salas, MD, PhD; Maria Pisu, PhD; Yendelela L. Cuffee, MPH; Damien Larkin, MA; Sharina D. Person, PhD; Bruce Barton, PhD; Catarina I. Kiefe, PhD, MD; and Sandral Hullett, MD, MPH

Background: Storytelling is emerging as a powerful tool for health promotion in vulnerable populations. However, these interventions remain largely untested in rigorous studies.

Objective: To test an interactive storytelling intervention involving DVDs.

Design: Randomized, controlled trial in which comparison patients received an attention control DVD. Separate random assignments were performed for patients with controlled or uncontrolled hypertension. (ClinicalTrials.gov registration number: NCT00875225)

Setting: An inner-city safety-net clinic in the southern United States.

Patients: 230 African Americans with hypertension.

Intervention: 3 DVDs that contained patient stories. Storytellers were drawn from the patient population.

Measurements: The outcomes were differential change in blood pressure for patients in the intervention versus the comparison group at baseline, 3 months, and 6 to 9 months.

Results: 299 African American patients were randomly assigned between December 2007 and May 2008 and 76.9% were retained throughout the study. Most patients (71.4%) were women, and the mean age was 53.7 years. Baseline mean systolic and diastolic pressures were similar in both groups. Among patients with baseline uncontrolled hypertension, reduction favored the intervention group at 3 months for both systolic (11.21 mm Hg [95% CI, 2.51 to 19.9 mm Hg]; $P = 0.012$) and diastolic (6.43 mm Hg [CI, 1.49 to 11.45 mm Hg]; $P = 0.012$) blood pressures. Patients with baseline controlled hypertension did not significantly differ over time between study groups. Blood pressure subsequently increased for both groups, but between-group differences remained relatively constant.

Limitation: This was a single-site study with 23% loss to follow-up and only 6 months of follow-up.

Conclusion: The storytelling intervention produced substantial and significant improvements in blood pressure for patients with baseline uncontrolled hypertension.

Primary Funding Source: Finding Answers: Disparities Research for Change, a national program of the Robert Wood Johnson Foundation.

Ann Intern Med. 2011;154:77-84. www.annals.org
For author affiliations, see end of text.

African Americans are 21% more likely than white persons to die of heart disease and 49% more likely to die of stroke (1). Despite many attempts to close racial and ethnic gaps in risks for cardiovascular diseases, such as hypertension, important disparities persist (2). Motivated by these findings, we sought to develop and test a novel, evidence-based, and culturally appropriate intervention to improve blood pressure control in African Americans.

Blood pressure control is complex for any patient with hypertension and requires long-term adherence to medication, diet, exercise, and medical follow-up. This complexity contributes to the widely documented poor control among patients in general (3) and African Americans in particular (4). African Americans are more likely to have hypertension, less likely to achieve control, and more likely to have end-organ damage than white persons (4). These differences in blood pressure control are partially explained by identifiable barriers, such as unhealthy diet and lack of exercise promoted by environmental factors (5), limited access to clinicians and medicine, distrust of the medical system (6, 7), and poor medication adherence (8, 9). However, interventions to overcome these barriers have had mixed results (10).

Programs that target vulnerable populations may fail for several reasons, including lack of cultural relevance. Although the resulting intervention may be conceptually sound, the lack of cultural relevance may decrease effectiveness (5). Emerging evidence suggests that storytelling, or narrative communication, may offer a unique opportunity to promote evidence-based choices in a culturally appropriate context. Stories can help listeners make meaning of their lives (11, 12), and listeners may be influenced if they actively engage in a story, identify themselves with the storyteller, and picture themselves taking part in the action (13). Because narrative communication can break down cognitive resistance to behavior-change messages (14), we hypothesized that it would be a suitable mechanism for ad-

See also:

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Editorial comment 129
Summary for Patients I-24

Web-Only
Appendix
Appendix Tables
Appendix Figure
Material from Intervention DVDs
Conversion of graphics into slides


THE BOSTON GLOBE • MONDAY • MARCH 21, 2011
g
HEALTH
What's her story?
SHARING TALES MAY BE GOOD MEDICINE FOR ALL KINDS OF ILLS
HEALTH
WOMEN WARY OF HORMONE USE
OPERA
'DEATH' GOES SOUL-SEARCHING
ART
GARDNER NAMES NEW CURATOR

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University of Massachusetts Center for Health Equity Intervention Research

Funded by NIMHD grant 1P60MD006912

UMASS MEDICAL SCHOOL

UMASS BOSTON

Dissemination of Storytelling Approach

- CHEIR
  - Parent-child communication for sexual health
  - Weight loss in lower income post-partum mothers
  - Hypertension in community health centers
  - Research literacy
- Hypertension
  - Kaiser Permanente of Southern California
  - Greater Detroit Area Health Council
  - Rural Vietnam
  - Veteran's Administration
- Other topics
  - Hepatitis prevention in Asian populations
  - Breast cancer survivors
  - Perinatal care for low-income Hispanic women

Storytelling...

- Is a powerful intervention technique for improving health behavior in a culturally, linguistically sensitive manner.
- Is suited for low-literacy populations.
- Has a strong conceptual foundation.
- Can impact the storyteller and the listener.
- Taps into universal human experience to empower and motivate.

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- More webinars on this topic?
- New topics you want to tackle or learn more about?
- Innovative work that you want to share?
- A question you want to pose to your colleagues?

Contact us at equity@gih.org

Attend the GIH Fall Forum,
an annual gathering for funders interested in health policy.

Visit **www.gih.org** for details and to register.