The Second Annual
State of Asian Women's Health in MA Conference

Tufts University School of Medicine

May 21, 2014

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. Get care ASAP to optimize health during pregnancy - pre/postnatal, pre-contraception, family planning, etc.
    b. Important to recognize understand and address barriers to care (breastfeeding in the workplace)
    c. Identity/cultural/family stories are critical to maternal reproductive health
    d. Foster awareness toward sexual health, keeping in mind generational differences.
2. Do you see any overlapping issues or concerns?
    a. Lack of communication + collaboration among communities
    b. Cultural/clinical awareness in nutrition/diets
        i. Weightwatchers
        ii. cultural eating habits
        iii. healthy interactions
        iv. nutritional guide - culturally sensitive
3. What can we do to address these concerns?
    a. Health advocates in the community
    b. Mother as resource for next generation
    c. peer groups
    d. discussing taboo subjects e.g. contraception
    e. traditional family models may negatively impact health care for women
    f. confidentiality
    g. Lack of funding for community education, inadequate data (qualitative/quantitative - both needed! why?, what?) translation into meaningful programs

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. Need for data pertaining to specific ethnicity
    b. Prevalence rate of liver cancer and Hepatitis B for Boston
    c. National vs local data
    d. Poverty rate/Information
    e. Targeted population for cervical cancer screening
    f. Medication adherence & cultural barriers in the case of asthma
2. Do you see any overlapping issues or concerns?
    a. Need for disaggregated data (age/georgraphical breakdown)
    b. Healthy screening procedures
    c. Recall issues
    d. Socioeconomic issues (literacy level/job)
    e. Cultural differences in understanding of info sharing
    f. Immigration/adjustment issues: language, employment, child-bearing
    g. Mental health
    h. Ethnicity data
    i. Trust building
3. What can we do to address these concerns?
    a. Peer support group
    b. Health education
    c. Increase awareness
    d. cultural competency
    e. for data - advocate for actionable behaviors
    f. Health promotion
    g. Need to understand the importance of geographical & other health-related data)
    h. Tailored messages for different targeted groups
    i. Engage the community & key stakeholders

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. Understand/learn about similarity between data for Latinos and for AAWPI communities
    b. Risky behaviors of AA men led to domestic violence at homes for women
    c. Awareness to liefstyle since statistics show higher rates of heart disease and diabetes
    d. Data contradictory to stereotypes of Asian American women behind happy, serene, healthy
    e. especially the myth that AA women being thin
    f. the need to change this perspective
    g. Awareness of high rates of infectious disease (salmonella)
    h. Reporting issues with hepatitis
    i. Instead of going to doctors, go to drug stores and over the counter drugs on advil leads to kidney-related issues (different cultures have different medicinal practices. How to work with that?)
    j. Importance of preventive care
    k. Better education/communication for elders specifically that are more culturally-sensitive
    l. Poor diet of Asian American community, also Latinos
2. Do you see any overlapping issues or concerns?
    a. Data collections and limitations on standards (racial classifications)
    b. Needed recognition of each Asian group's special background/circumstances
3. What can we do to address these concerns?
    a. Set standards when collapsing data into certain labels
    b. Look closely at:
        i. immigration status/birthplace
        ii. number of years in U.S. (acculturation)
        iii. Education level
    c. Make stats more local
    d. Need to surpass language barriers when closing gaps in health care disparities - within all Asian ethnic groups
    e. Importance to address the differences in data collection and limitations between national, state and city statistics.
    f. Even though overall Asian health is good, there are clear differences between the ethnic groups.
    g. Education
    h. Advocacy - more funding from Govt and regulations
    i. Cultural sensitivity - sensitive to all grassroots communities
    j. Need better community outreach
    k. Make institutions accountable

l. Breaking down data to look at subgroups (different ethnicities have different cultures & make institutions more aware and accountable for groups)
m. Resources for more specific data and making data available.

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. Available data about population and subpopulation health conditions and status (however it's collected and organized, and for what purposes) needs/ought to be dissected further (and made more useful for the array of purposes community health advocates rightfully have.
    b. Having insurance (formally, as in Obamacare) does not mean that the insured have access or can use the healthcare delivery system.
2. Do you see any overlapping issues or concerns?
    a. How can any of this information or these concerns 'actionable'? What does it mean to reflect upon these population needs and shortcomings in providing people what they need in their claim upon health, given the current state and resources of the healthcare delivery system?
    b. A great many concerns are not directly addressed by the data.
    c. Research data seems to be driven by business interests, such as the hospital conglomerates themselves, or by governments who are driving their own interests (concerns for optimizing human health may not be included in those; sometimes governments only address health problems when they reach a crisis state, so there can be an emphasis upon describing medical conditions that demand treatment, such as diabetes, cancer, stroke, heart disease, HIV/AIDS and other STDs, transplantation, end of life issues, disabilities, etc. However, the claims inherent in a 'right to health' (to which advocates appeal) seem not to be understood in terms of a right to HEALTH, not merely the de facto 'right' to remedial healthcare after a preventable condition has been diagnosed.
    d. Mental health data is not robust, so we're barely addressing mental health issues.
    e. Bidirectional mental health data is very important for understanding physical health because they are inter-related in each psychophysical unity.
    f. A useful and adequate database for the concerns of this conference requires research in factors of language, culture, accessibility, and health literacy.
    g. Our workgroup wanted a translation or interpretation of services that Federal law calls a human right in all services in Massachusetts. Chart (in several columns) the Federal entitlements with the available health-related services in Massachusetts.
    h. Healthcare providers and insurers should know how to use cultural competency resources, including phone interpreters for each of the widely-used languages in a region.
    i. Over two generations, immigrant medical conditions begin to match the health condition of the host population which receives them. In some (many?) cases, this socialization may not be good for the immigrants, whose health conditions may worsen by copying what the actions they see in the majority around them, as they seek to assimilate into 'the majority'! Asian populations with little or no heart disease, obesity, cancer, or stroke (in the 1950s) saw their grandchildren of immigrants in America suffering the same diseases, at the same rates, after two generations. However, this observation may be confounded by impacts of global homogenization through marketing and powerful digital and other media.
3. What can we do to address these concerns?
    a. Insurers and providers can/could and should provide multi-language websites and literature.

b. Can public conversations about public health be conducted in ways that are sensitive to populations' moral, religious, cultural beliefs?
c. Increase community participation and engagement
d. Listen to and engage communities (Who would do that? Governments, AWFH and other nonprofits/NGOs, insurers and providers? Presumably EVERYONE would see this as 'best practice' or be obligated to evidence engagement with identifiable communities, such as ethnicities and nationalities: Asians, Asian women, etc.)
e. Seek to understand these communities' needs.
f. Explore and perhaps establish 'country of origin' partnerships for diagnostics and interventions (e.g. Asians in America could be 'matched' with 'country of origin' medical needs, if DNA-related research could yield scientific evidence for improved treatment; concerned Asian-Americans might donate to 'nation of origin' populations because of empathy for 'those like us'.
g. More research on effective prevention ('prevention research' as HSPH and other schools of public health have). Prevention research should focus on health-supporting living/lifestyles. Currently-available data focuses on post-diagnosis interventions in preventable conditions that result in preventable suffering. These preventable conditions are all laden with avoidable costs, so prevention research, while hard to quantify by more widely used healthcare economics methods, should somehow benefit those who apply or translate the prevention research into evidence-based policies and interventions.

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. Ethnically, Vietnamese have the highest rate of asthma, while Chinese have the highest rate of heart disease and Hepatitis B
    b. Even though many have insurance, they do not use it.
    c. Data may not reflect the truth because of the limited numbers
        i. Does not include undocumented
        ii. Not significant enough to reflect the community
    d. Many Chinese immigrants – do not reveal info, disclose personal facts (lack of trust in the government)
    e. Unintended pregnancies, mental health, binge drinking – surprising facts
    f. High rates of cancer – second hand smoke leads to lung cancer, also high rates of liver cancer in the community
    g. High rates of infectious disease
2. Do you see any overlapping issues or concerns?
    a. More about Affordable Care Act info desired – lots of transitions in MA over the past few years
    b. Different data found similar results (commercially, state, national, provider, etc.)
    c. Ethnic lumping skewing data, APIs appear to be doing well generally
        i. But some specific issues highlighted
    d. Language barrier to collecting data, might not understand, skew results
    e. Alternative treatments may appear to be doing well – no data on that
        i. Ask herbalists/Eastern medicine providers
        ii. Not reimbursed by insurance generally
        iii. Some hospitals offer holistic care
    f. Pretax to pay for alternative care – flexible spending accounts, based on employers, don't need to go through insurance claims
3. What can we do to address these concerns?
    a. Eastern medicine be recognized and reimbursed
    b. Provider/cultural sensitivity in health plans
    c. Officials/government workers reflected by ethnicity and demographics
    d. 9-5 appointments don't work, bring services to immigrants to accommodate their schedules, find where they are
    e. More conversation regarding gender differences in health data, why men doing "better," disparities in data
    f. Increase openness of immigrants to discuss taboo issues, reduce stigma
        i. Start with small community
    g. Fear of knowing something if not directly affected, but education important
    h. Breaking down cultural taboos
    i. Address it generationally – address by age group?

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. About the alarming rates of lung cancer, liver cancer.
    b. How jumbled and un-connected a lot of the data is.
    c. The need to be more aware of fine grained cultural issues in exploring/collecting and then using data – the Mainland Chinese practice of cigarettes and alcohol as visiting gifts, e.g.
    d. Similarly, greater attention to reasons behind some of the data – in particular health issues for single female head of household – Mom sacrifices self, neglects her own health and well being.
    e. Much of the data would be richer if connected to/cross tabbed with the social determinants of health. Occupation (high asthma rates for Vietnamese women – nail salon employment?) (high male exposure to floor finishing toxics, lead, asbestos?) (employment in hospitality industry?) (ditto sex industry?)
2. Do you see any overlapping issues or concerns?
    a. The need for better disaggregation and overall coordination.
    b. Better, perhaps community informed, reading of the data – does higher insurance rate, but lower medical test rate correlate with deductibles?
3. What can we do to address these concerns?
    a. Encourage activism around health and the use of health data. The worry expressed in our group was that we would become "social historians" recording this information, but not using it.
    b. More community informed discussion of data. Are we accurately collecting information about mental health or sex work, for example, if we are not aware of and allowing for the social stigma that may mask information because of reluctance?
    c. Paying greater attention to how we use, or might use, what we learn. Related to this, understanding that the use of data may create positive feedback loops (in relation to data collection) by increasing the accuracy and fine-grained quality of the information gathering process.
    d. The question was asked, "should community activists, to whatever extent possible, be driving data collection?" Right now it seems like monetary concerns are the primary engine.
    e. There should be more effort to have communities engaged at all levels in regard to data collection, analysis and dissemination.

First Breakout Session (Data Panel)

1. What did you learn from this presentation?
    a. How far we still need to go, despite all of this great progress
    b. Commercial health plans have very rich data → need broader access to this
    c. More robust data needed, with a *primary focus on disaggregated data*
    d. Need to be cognizant of the trust that needs to be built in order to have these dialogues with patients around such personal information
        i. History of data being used discriminatorily
2. Do you see any overlapping issues or concerns?
    a. Data collection and sampling
        i. Sometimes samples are too small to get a real depiction of what is going on in a specific group
        ii. Missing needs by lumping South Asian with Southeast Asian and East Asian; differing language needs in these groups
        iii. Health disparities v. health inequities
            1. Address the social determinants at the root of inequities
3. What can we do to address these concerns?
    a. Hold policymakers accountable in different locations via community activism (not every community has the kind of activism and resources that we have in Boston)
    b. NIH allocating increased funding for research on women and ethnicity-based inequities
    c. Education and outreach to institutions, explaining how strides towards addressing inequities and disaggregating data will benefit both the patient and their practices.
        i. Make sure to *involve the community* in designing materials and campaigns that are locally and culturally relevant and competent
            1. Focus groups, other qualitative research methodology
                a. This is time intensive, but very important!!!
    d. Unfunded mandates not enough, federal funding must back them
    e. Look into the best methods to relay information to different populations
    f. Change paradigm→ feds receive data from the community up
    g. More commonalities among different federal agencies

Second Breakout Session (Provider Panel)

1. What did you learn from this presentation?
    a. Was unaware of the Cambodian community health issues in youth
        i. Ex. Drinking, generational gaps/differences
        ii. Silence in lived experiences and traumas
    b. Saheli – deals with Southeast Asian community and domestic Violence
        i. Transformation in being strong center for community from starting small
    c. Mental Health of certain groups brushed under the rug
    d. Lisa Wong
        i. Grounded, community capital, encourage fun ideas
        ii. Know how to reach people, approachable
        iii. Tackle obesity by door knocking (good idea)
        iv. Community created ideas/program
    e. Saheli Topics more engaging with topics about "manhood"
        i. LESS stigmatizing
2. Do you see any overlapping issues or concerns?
    a. Stigmatization of mental health in different AA groups
    b. Stigmatization of domestic violence in different AA groups
    c. Public health and mental health viewed as separate
    d. Mental health in Sampan News nearly not existence
    e. Mental health not well-tested research and product
        i. Value biomedical system (doctors, prescriptions, etc.)
        ii. Still a large debate about depression
    f. Not a large dialogue about sensitive topics
        i. First generation AA immigrants and mental health issues
            1. Manifesting in second, third, etc. generations
3. What can we do to address these concerns?
    a. System changes to get to root
        i. Lisa Wong suggests looking at bigger picture, improvements
        ii. Ex. Bringing A vs. B students
    b. Use "linguistic and diverse" populations
        i. Ex. People speak Haitian, Creole
    c. Empower community members to make change
    d. Community health worker model → Access
    e. Versus having institutions of power give platform to community to make decision, have a voice to improve their own lives
        i. VOICE, REPRESENTATION
        ii. ACCOUNTABILITY, TRANSPARNACY
    f. Symposiums, conferences, media education about sensitive issues

Second Breakout Session (Provider Panel)

1. What did you learn from this presentation?
    a. Learned about different services and the specific communities they serve
    b. Prompted to think about how the dynamic of the group affect the structure of the organization
    c. Organizations become more open to other communities nowadays
    d. There is hope for young people who are not shackled to become activists
    e. How to keep/embrace the ethnic identities people bring to this country
        i. What are the traditions that one should keep or get rid of with forced assimilation?
2. Do you see any overlapping issues or concerns?
    a. Mental Health issue: individuals in the community are often pained by the experience to have to give up their culture
        i. Ex. Different cultural practices and holidays
    b. Coming to terms with multiracial identities
        i. How to find reconciliation
    c. Even the multiple dual identities that we have (being Asian American, Chinese American, etc.)
        i. We are forced to pick a definite label/identity for ourselves
    d. The stereotype of AA as the perpetual enemy
    e. Screening and evaluation
        i. Organizations still struggle to capture data
    f. Data is still 10 years behind. Doesn't reflect how it is now
3. What can we do to address these concerns?
    a. Clinical practices very Western, not serving our community
    b. Little data on Asian Americans (most conducted in California and not really elsewhere)
    c. Need more research work and conferences in Boston area
    d. Need to have better training for clinicians
    e. More dedication to data collection
        i. needs actual statistics to get funding and resources
    f. Need better diagnostic guidelines for clinicians to have more sensitive approach
        i. Specifically programs of Asian Americans
    g. Manuals that speak of Asian American experience and themes and specific ways to intervene
    h. Finding ways to reach out to specific groups for research purposes
    i. How to make it so that people would feel comfortable seeking mental health services
        i. Changing the word "mental health"
        ii. Huge stigma on the phrase
    j. Adjusting different forms of therapy
    k. Really need to question how do we define/categorize

Second Breakout Session (Provider Panel; my group focused on Domestic Violence)

1. What did you learn from this presentation?
    a. DV and its prevention as a taboo subject can become supported by the community through grassroots work
    b. Framing DV as an issue that impacts children is effective for increasing community support
    c. Effectiveness of working from a survivor empowerment-based model
    d. Community-embeddedness increased impact
    e. Importance of accountability → if you raise awareness around DV, how will you provide the necessary services?
2. Do you see any overlapping issues or concerns?
    a. Overlap between DV and mental health, overall health, and health-related behaviors
    b. Violence in non-heterosexual relationships → how does support around violence in the home and healthy relationships come into play in the other programs we heard from
    c. Lack of representation in the data of DV in certain community → from the medical standpoint these issues may "not exist" and there are no resources for them
3. What can we do to address these concerns?
    a. More culturally-competent/sensitive methods of screening for DV within a healthcare setting
    b. More education for survivors as they transition to shelters/other spaces around regulations, services, mental health, etc.
    c. Advocacy around helping maintain survivor stability → jobs, kids in school, etc.
        i. What can shelters do to help women develop marketable skills if husband was the breadwinner
    d. Keep in mind that survivors need a support network that speaks their language, understands their culture, etc.
    e. Educate community about DV as an issue and services available

Second Breakout Session (Provider Panel)

1. What did you learn from this presentation?
    a. There are different types of diabetes, and there is gestational diabetes, which afflicts pregnant women without previous diagnosis of glucose problems. Asian women who may have higher prevalence of glucose metabolism issues may also have higher incidence of gestational diabetes mellitus (GDM). Screening is recommended for such women who are at risk of GDM. Gestational diabetes affects 3-10% of pregnancies, depending on the population studied.
2. Do you see any overlapping issues or concerns?
    a. Does immigrant health TEND to decline through socialization and assimilation?
    b. Could border crossing data re: health in refugee populations seeking economic opportunities help inform immigrant settlement services?
    c. How can researchers and clinicians and policy makers think **most rationally** about human needs? Are these meta-critical or philosophical/ethical issues?
    d. We want to reduce harms overall, including harmful inputs (to each person) which elevate her risks of suffering from illness and disease.
    e. Concerns for each woman are number: health, safety, longevity, happiness, and productivity. She's not only a medical status.
    f. We want to protect the human rights AND human health and the multidimensional futures of incoming populations.
    g. Some interests and concerns are shared across a number of roleplayers/stakeholders.
    h. There's possible misuse of any data which is collected. How can misuse be prevented?
    i. What is collected as 'data' can be 'informationally' ambiguous. Data can include ambiguous elements.
    j. Could some interventions place undue stress upon disadvantaged and otherwise at risk persons, such as children?
3. What can we do to address these concerns?
    a. 'Research ethics' (a rather robust discipline) could inform us here (in deepening our concerns).
    b. Establish stronger understandings (in target populations) in the behavioral correlates of disease and health: diet, smoking, exercise. Encourage self-care and caring about one's own health and the health of one's own family and of one's neighbors.
    c. Convene groups of 'willing collaborators' (who share purposes and subpurposes) to carry these deliberations further.
    d. Search for innovate ways to increase health literacy
    e. Intergenerational approaches might help researchers better understand how generations communicate (unhealthful behaviors) across generations.
    f. Cross-sector collaboration
    g. Frame behavioral interventions for success by making them educational, fun, and otherwise appealing.