

# Cultural Challenges to Engaging Patients in Shared Decision Making

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September 17, 2015

Houston, Texas



This idea of focusing on patient-centered medical care has been one that's come to the forefront in the last decade and we've heard a lot about that.

## Context

- **National attention has been directed to achieving patient-centered medical care:**
  - Incorporating patients' references
  - Increasing patient involvement in decision making and ensuring informed/shared decisions
- **Improving patient-centered care has been identified as a method for reducing disparities in health outcomes**



National attention has focused on increasing patient involvement in decision-making and ensuring that decisions are informed and shared. The second bullet is one that I really want to focus on, the idea that improving patient-centered care has been identified as a method for reducing disparities and health outcomes. If we believe that by engaging patients in their care, by helping them make better, more shared decisions and being more patient-centered that we can overcome health disparities then we really need to think about what those challenges to doing that might be.

## Patient Centered Care

**“Health care that respects and honors patients’ individual wants, needs and preferences and that assures that individual patients guide all decisions.”**

—Institute of Medicine, 2001

Committee on the Quality of Health Care in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; 2001.



This is the Institute of Medicine’s definition – that patient needs, patient preferences, and involving patients in decision-making is what patient-centered care should be.

## Informed/Shared Decision Making

- **Informed decision making (IDM)** is when an individual understands the nature of the disease or condition being addressed, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his/her preferences and values or elects to defer a decision.
- **Shared decision making (SDM)** is when a patient and his or her healthcare provider(s), in the clinical setting, both express preferences and participate in making treatment decisions.

Briss P, Rimer B, Reilley B, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med.* 2004 Jan;26(1):67-80. PMID: 14700715.



Whenever I talk about shared decision-making I usually try to include this paper by Briss, Rimer and colleagues that came out in 2004 because it's the only paper that does a really good job of separating informed and shared decision-making; a lot of times those concepts get linked. What do we mean by engagement and activation? Informing patients so that they can make a good informed decision is one thing. Involving them in that decision and whether that means that we nudge them to be more active in that decision. The challenges to these are somewhat different although they may be related.

## Defining Culture

- **The sum of attitudes, customs and beliefs that distinguishes one group of people from another. Culture is transmitted through language, material objects, ritual, institutions and art from one generation to the next.**
  - Often use race/ethnicity as a proxy for culture



When I thought about this talk I realized I didn't really have a handy good definition of what culture meant. I just went online and found this one which I thought was useful for us to have today because we want to be thinking broadly and this is broad definition of the things that make up a group of individuals, that are passed down from one generation to the next. And, we often use race and ethnicity as a proxy for culture.

## For Today

- **We will focus broadly on culture as it relates to “world views”.**
- **Examples/evidence will:**
  - Primarily use race/ethnicity and language to represent culture, understanding that culture is broader than just race/ethnicity
  - Largely focus on cancer care, understanding that these issues relate to SDM across conditions
  - We will not focus on literacy (addressed in other talk)

So I will be trying to focus on culture thinking about it as it relates to world views of a group.

## What is Known: Impact of Culture on Health

- **Racial/ethnic and less acculturated minorities have been shown to receive care differentially from the white majority**
  - Less preventive services
  - Later stage diagnosis
  - May not receive all treatments



For today I'm going to primarily use race, ethnicity, and language to represent culture because that's the data that I have and the data that tends to be available.

But culture is broader than just race and ethnicity. I will be providing examples and evidence from some of my own work and referencing work of others largely on cancer. That's the area in which I work -- the continuum from screening, new treatments, survivorship -- but the issues and the challenges related to shared decision-making are across conditions.

In terms of what we know about the impact of culture on health, racial ethnic and less acculturated minorities have been shown to receive care differentially from the white majority. Unfortunately, we have seen this for years and in some cases for decades. Minorities tend to receive less preventive services, and are at later stages at diagnosis. This is true for cancer and for other conditions as well. And, once diagnosed they tend to sometimes not receive all of the treatments that are available.

## Examples

| Screening                                  |  |
|--|--|
| Hossain et al., 2011                       | <ul style="list-style-type: none"><li>Lower rates of prostate specific antigen (PSA) testing in African American (AA) vs. white men</li></ul>  |
| Hawley et al., 2008<br>Shokar et al., 2010 | <ul style="list-style-type: none"><li>Lower rates of colorectal cancer (CRC) screening in minorities vs. whites</li></ul>  |
| Diagnosis                                  |  |
| Chatterjee et al., 2013                    | <ul style="list-style-type: none"><li>AA women more often diagnosed with late-stage breast cancer than whites</li></ul>  |
| Treatment                                  |  |
| Baldwin et al., 2005                       | <ul style="list-style-type: none"><li>AA patients less likely to receive recommended colon cancer treatment than whites</li></ul>  |
| Dehal et al., 2013<br>Corso et al., 2015   | <ul style="list-style-type: none"><li>Disparities in breast cancer treatment and outcomes</li><li>AA patients less likely to receive recommended lung cancer treatment than whites</li></ul> |
| Survivorship Care                          |  |
| Palmer et al., 2015                        | <ul style="list-style-type: none"><li>AA patients report more barriers to breast cancer follow up care than whites</li></ul>   |



This table is a sample of cancer studies that have shown this. Some work has shown differences in screening, but we tend to see that minorities have lower rates of screening than whites.

Regarding diagnosis, a recent paper showed what we have known now for decades -- that African-American women tend to be diagnosed with later stages of breast cancer than whites. And, down the continuum there we see these differences. So why? Why do these exist? One of the reasons that we know is that access to care has been a problem in our country. Another reason may relate to the process of care, that is, our ability to provide patient-centered care and make sure that patients are involved and engaged in decisions.



## Culture and Shared Decision Making

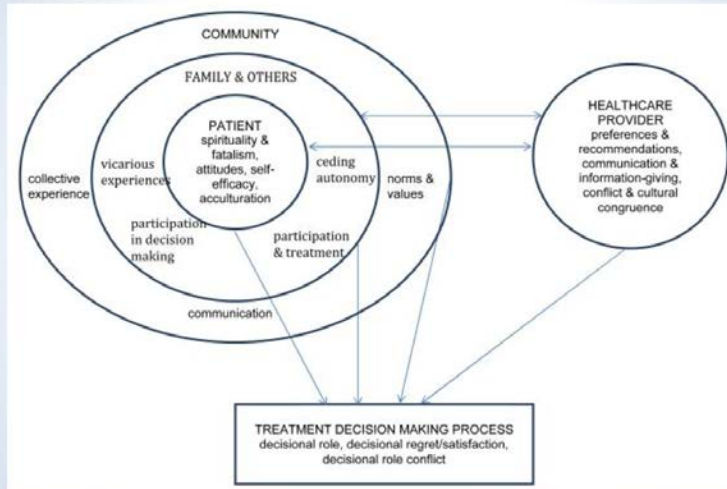
- Why might disparities exist?
- Mead et al., *AJPH* 2013 identified 5 themes related to SDM for cancer care among racial/ethnic minorities:
  - Treatment decision making
  - Patient factors
  - Family and important others
  - Community
  - Provider factors

Mead EL, Doorenbos AZ, Javid SH, et al. Shared decision-making for cancer care among racial and ethnic minorities: a systematic review. *Am J Public Health*. 2013 Dec;103(12):e15-29. PMID: 24134353.



In a paper by Mead and colleagues published in the *American Journal of Public Health* in 2013, five themes which relate to shared decision-making for cancer care were identified.

## Framework



Mead EL, Doorenbos AZ, Javid SH, et al. Shared decision-making for cancer care among racial and ethnic minorities: a systematic review. *Am J Public Health*. 2013 Dec;103(12):e15-29. PMID: 24134353.



Here is how all of these factors work together to influence the decision-making process. The patient is nested within family and others. Family and others are within a community. All of these are interacting with the healthcare provider and the healthcare team. And then driving towards influencing the treatment decision-making process.

## Examples

| Theme                    | Examples From Research   |
|--------------------------|--|
| Patient factors          | <ul style="list-style-type: none"><li>• Perceived/actual discrimination</li><li>• Personal beliefs</li><li>• Spirituality</li><li>• Trust in providers</li></ul>                                   |
| Treatment decisionmaking | <ul style="list-style-type: none"><li>• Perspectives on how decisions should be made</li><li>• Differential understanding of risk/benefit information</li><li>• Variation in preferences</li></ul> |
| Family/others            | <ul style="list-style-type: none"><li>• Role of others in decisionmaking</li></ul>   |
| Community                | <ul style="list-style-type: none"><li>• Existence of networks, support groups</li></ul>  |
| Provider factors         | <ul style="list-style-type: none"><li>• Training</li><li>• Communication style</li><li>• Experiences with health system</li><li>• Their own preferences</li></ul>                                  |



This table shows examples for each of the domains to get us thinking about some of the issues that exist and how these are challenges.

On the patient side what might differ among different cultures that could be associated with differences in decision-making and the ability to engage patients, include things like perceived or actual discrimination, personal belief systems, spirituality, and trust in providers

In terms of the actual decision-making, domains include: perspectives on how decisions should be made, and a differential understanding of risk and benefit information and variation in preferences that may relate to patient or personal factors.

The role of family and others in decision making may vary.

And then on the community and the provider side I don't have data from my own work to share today but we know that these may differ by cultural group.

## Data Sources

- **Population based study of 1,435 colorectal cancer patients from Atlanta and Detroit**
  - 26% African American, 68% white
- **Population based study of 2,290 breast cancer patients from Detroit and Los Angeles**
  - 33% African American , 12% Latina high acculturated, 13% Latina low acculturated, 42% white
  - Acculturation measured using the Short Acculturation for Hispanics Scale (SASH)
- **Currently ongoing population based study of 2,000 breast cancer patients in Atlanta and Los Angeles**

Griggs JJ, Hawley ST, Graff JJ, et al. Factors associated with receipt of breast cancer adjuvant chemotherapy in a diverse population-based sample. *J Clin Oncol.* 2012 Sep;30(25):3058-64. PMID: 22869890.

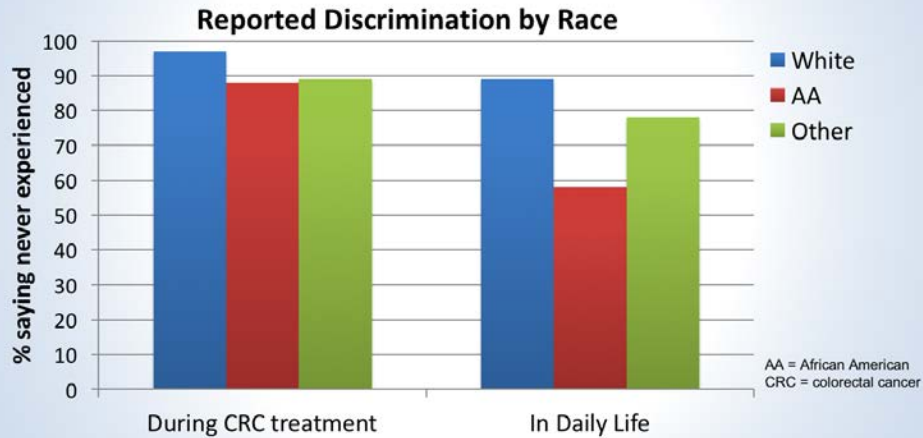


These are examples to get us thinking about differences. Most of these are from population-based studies conducted by my group at Michigan and the Ann Arbor VA called the Cancer Surveillance and Outcomes Research Team. We've partnered with the NCI funded cancer registries to survey large numbers of cancer patients usually within 6 to 9 months of their diagnosis.

The first study is a population-based study of colorectal cancer patients in Atlanta and Detroit. We purposely oversample African-Americans so that we can get representation and look at differences. This study was focused on trying to understand reasons for differences in receipt of chemo therapy appropriately and to focus on racial and ethnic issues. The next two studies are more my area of breast cancer research. One is a completed study and one is a current study, again, both population-based, both oversampling African-American and Latina patients. And I just want to note here the second bullet under the second bullet that to determine acculturation we use the short acculturation for Hispanic scale otherwise known as the SASH. And it's relevant because it is a language-based scale and it asks people the degree to which they're comfortable in Spanish and English in thinking, reading, and talking. And so that's where the overlap among literacy and language and culture becomes a little bit blurry. But we were able to categorize our patients into low and highly acculturated based on that existing scale.

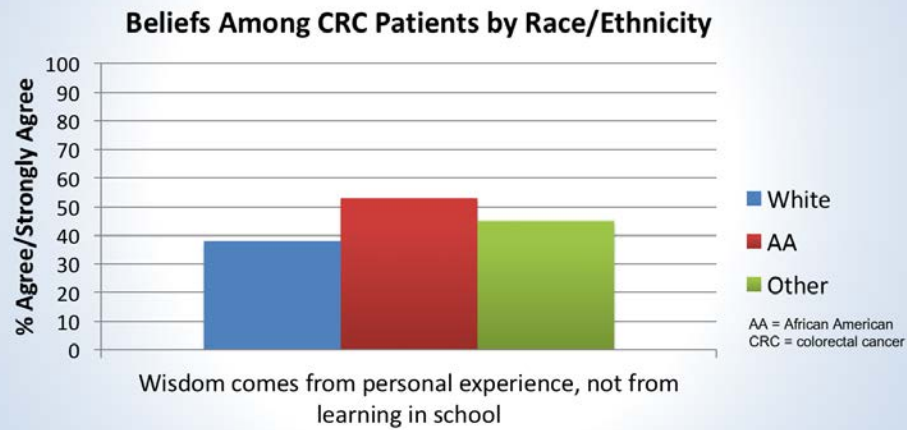
So moving into one of the first points that I mentioned as to why might we have challenges engaging patients in shared decision-making and in the provision of patient-centered care?

## Perceived Discrimination



So moving into one of the first points that I mentioned -- why might we have challenges engaging patients in shared decision-making and in the provision of patient-centered care? One reason might be because patients have different experiences with discrimination, real or perceived. From colorectal cancer patients, we asked them to indicate whether they had experienced discrimination during their colorectal cancer treatment and then in a separate question we asked the same for their daily life. This graph shows that for the most part patients did not feel that they had been discriminated against during their treatment although the African-American and other racial ethnic groups -- largely Hispanic and Asian patients -- did report so more often than did their white counterparts. But when we looked at the in daily life question we're seeing significant differences between white patients and the other racial and ethnic groups. So, this reminds us that people perceive that they experience discrimination and how that may affect them as they approach engaging in the health system.

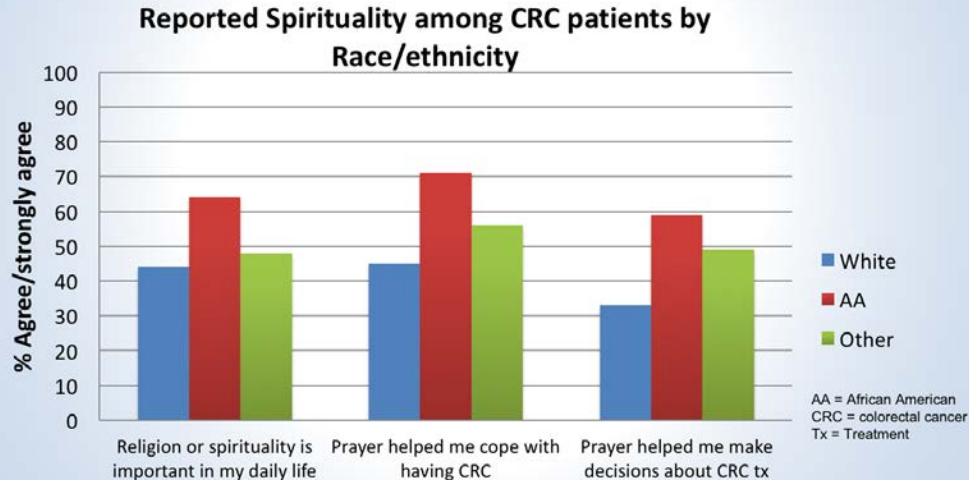
## Personal Beliefs



Personal beliefs, belief systems across cultures we know vary.

We had several questions where we were trying to understand how people approached learning and the role of education and information in their daily lives. In this question, where we asked if wisdom comes from personal experience, not from learning in school, the percentage who agree or strongly agreed showed slight differences between the white patients and patients of different racial and ethnic groups. We saw this pattern on all of our questions, which were not meant to be right or wrong, but rather meant to help us understand that people have different personal belief systems, which will impact how they interact with their healthcare and with their health providers.

## Spirituality

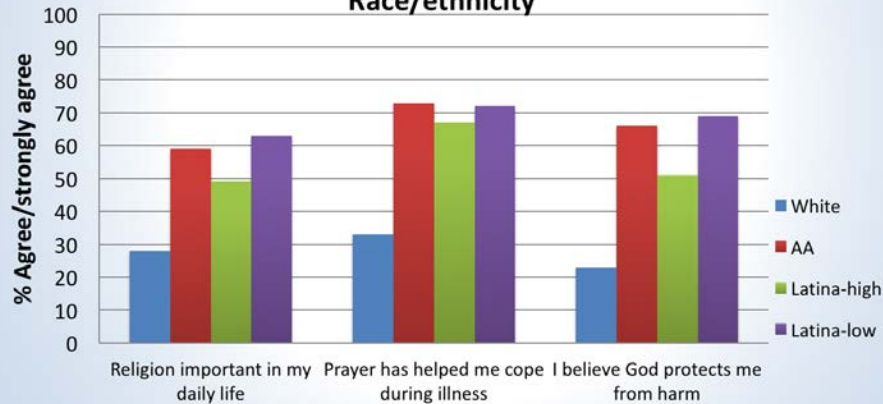


Spirituality is an area that has been studied more than the other two. This slide for colorectal cancer patients and the next for breast cancer patients, show responses from patients to the questions relating to their own perceptions of religion and spirituality in their lives.

In this slide, white patients are significantly less likely than African-Americans or other racial ethnic groups to agree or strongly agree with these questions. For, “Prayer helped me make decisions about treatment,” those views are going to impact how the patient interacts and engages with their provider in making shared decisions. And if the provider doesn’t assess the importance of religion and spirituality in the patient’s decision-making process then that’s a missed opportunity to understand how that belief system influences their treatment choices.

## Spirituality

Reported Spirituality among Breast Cancer Patients by Race/ethnicity



Here we see similar data for breast cancer patients. In this study we were able to characterize Latina patients into high or low acculturated based on the SASH measure. You can just see that the percentage of white patients who agree with these statements is significantly lower than for the other groups. We didn't have the exact same question about treatment but they were similar.



## Spirituality

|                        |  |
|------------------------|--|
| Umezawa et al.<br>2012 | Belief in divine control positively related to approach coping with cancer (i.e., positive reframing, active coping, and planning) in all ethnic groups. |
| Mollica et al., 2015   | Higher reported levels of spirituality associated with more satisfaction with prostate cancer treatment decision making                                  |

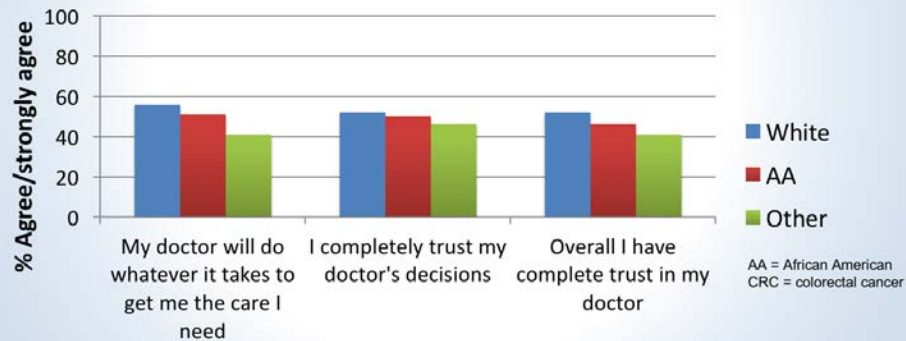
Umezawa Y, Lu Q, You J, et al. Belief in divine control, coping, and race/ethnicity among older women with breast cancer. *Ann Behav Med.* 2012 Aug;44(1):21-32. PMID: 22529040.  
Mollica MA, Underwood W 3rd, Homish GG, et al. Spirituality is associated with better prostate cancer treatment decision making experiences. *J Behav Med.* 2015 Aug 5 [Epub ahead of print]. PMID: 26243642.



These examples from the literature reinforce some of the data, highlighting these differences in spirituality and racial and ethnic groups.

## Trust in Providers

Trust in Providers among CRC Patients  
by Race/ethnicity



We've heard for some time that racial and ethnic minorities have lower trust in the healthcare system, harkening back to the 1932 Public Health Service's Tuskegee Study, and other studies. We were specifically interested in that issue in this colorectal cancer study and had a whole series of questions about trust.

I selected a few questions to show. According to responses to these questions, there is a good percentage of people who trust in their physicians and a good percentage of people in all racial and ethnic groups in our study who don't. So it is still an issue, but it doesn't seem to be particularly driven by race or ethnicity, at least in this study.

## Perspectives on Decision Making

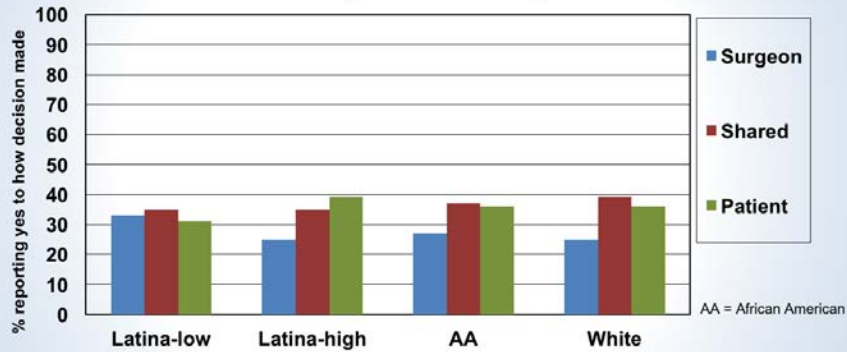
- **Research suggests that there are racial/ethnic differences in perspectives on**
  - Desire for involvement in decision making (autonomy preference)
  - Actual involvement in decision making
  - Decision outcomes



In terms of decision-making, research suggests that there are racial and ethnic differences. For example, in desire for involvement in decision-making, do people really want shared decisions and how do we handle that? What should we do? Should we nudge them? Should we respect their autonomy preference? Their actual involvement in decision-making is perhaps in part because of their desire for involvement. Regarding decision outcomes, things to consider include decision satisfaction and regret. The next slides are a few examples of that.

## Decision Involvement by Race/Ethnicity

### Breast Cancer Patients Report of How Decision Is Made by Race/Ethnicity



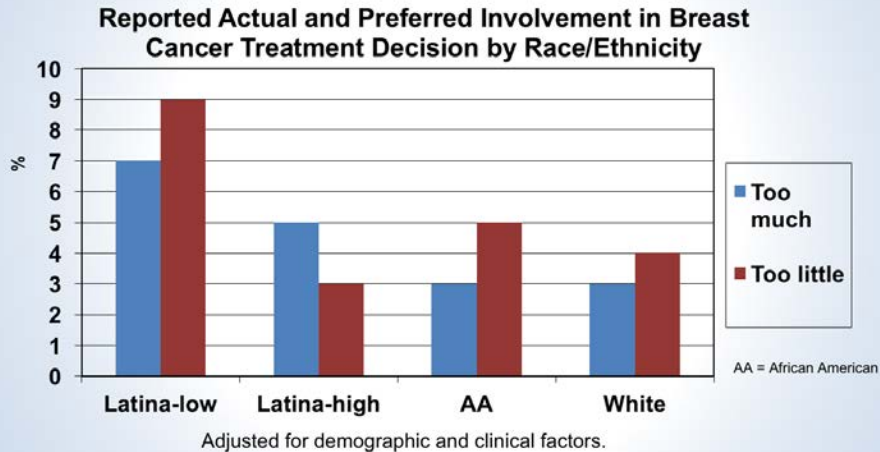
Stage 0, I, and II and no clinical contraindications to breast conserving surgery; adjusted for demographic and clinical factors, and sampling weights applied.

Reprinted with permission from Hawley ST, Griggs JJ, Hamilton AS, et al. Decision involvement and receipt of mastectomy among racially and ethnically diverse breast cancer patients. *J Natl Cancer Inst.* 2009 Oct;101(19):1337-47. PMID: 19720966. Copyright © 2009 Oxford University Press. All rights reserved.



These are more data from the breast cancer study in Detroit and Los Angeles; the racial and ethnic categories are along the bottom of this figure. This study used the controlled preferences scale published by Dagner and colleagues in the nineties. It asks patients how is the decision made? Was it on a scale from the surgeon made the decision to the patient made the decision and then we categorized that into surgeon-based, fully shared, or patient-based. This figure shows that for the most part the decision was either largely shared or patient-based with the exception of less acculturated Latina groups who are the most likely to report that it was a surgeon-based decision. So, there is definitely a difference in terms of how the decision was made for this group compared to the other groups.

## Match Between Actual-Preferred Involvement

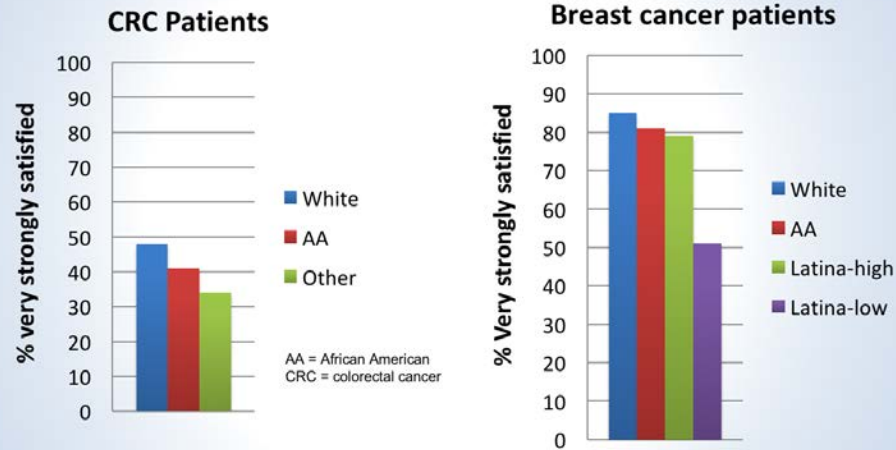


Hawley ST, Janz NK, Hamilton A, et al. Latina patient perspectives about informed treatment decision making for breast cancer. *Patient Educ Couns*. 2008 Nov;73(2):363-70. PMID: 18786799.



We looked at the difference between actual and preferred involvement to try to discern what was happening. Most patients said that they had the right amount of involvement. But among those who didn't, we were interested in whether they reported having had too much involvement or too little involvement and if that would help us understand the finding from this previous slide regarding the less acculturated Latinas. And in fact, they are the group who is the most likely to have discordance between how they wanted the decision to be made and how it actually was made; that is they were more likely to report that they had too little involvement than that they had too much involvement. So this finding supports the idea that for patients who really need to be involved in decision-making, we may need to urge them to be more active and more engaged, while recognizing and respecting their desire for less involvement, because sometimes they say they have too much. So it's a thin line to walk.

## Decision Satisfaction



Hawley ST, Janz NK, Hamilton A, et al. Latina patient perspectives about informed treatment decision making for breast cancer. *Patient Educ Couns.* 2008 Nov;73(2):363-70. PMID: 18786799.  
Lopez M, Kaplan C, Napoles A, et al. Satisfaction with treatment decision-making and treatment regret among Latinas and non-Latina whites with DCIS. *Patient Educ Couns.* 2014 Jan;94(1):83-9. PMID: 24207116.

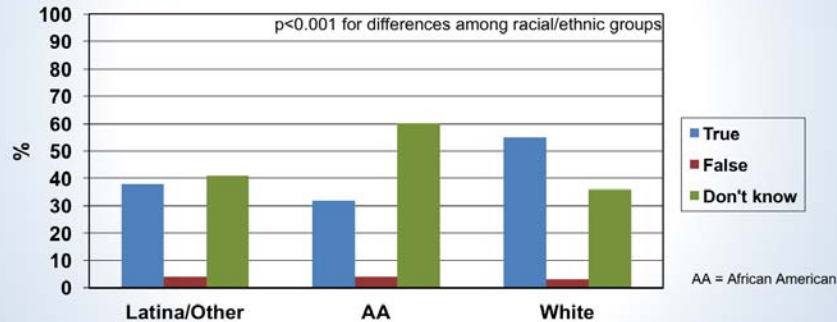


In terms of decision satisfaction, this slide shows data from studies of colorectal cancer patients and breast cancer patients, this study used Margaret Holmes-Rovner's measure of decision satisfaction to assess their decision after they had completed the treatment process. The data show an inverse linear relationship by race and decision satisfaction in the percentage of those who were strongly or very strongly satisfied; the white patients in both groups were the most likely to be very strongly satisfied and it declines from there. That is not something that we want to see. We want to see all patients being satisfied regardless of ethnicity. So you can see that the white patients in both groups were most strongly satisfied or were the most likely to be very strongly satisfied and then it declines from there.

## Understanding of Risk/Benefit

**Statement:** 5-Year survival is the same for lumpectomy + radiation as it is for mastectomy.

**Answer:** True.



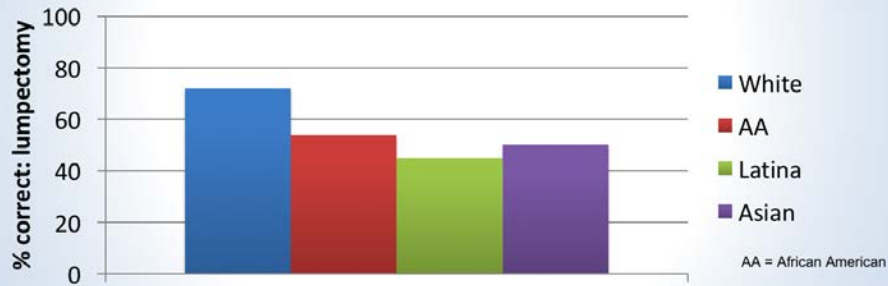
Reprinted from Hawley ST, Fagerlin A, Janz NK, et al. Racial/ethnic disparities in knowledge about risks and benefits of breast cancer treatment: does it matter where you go? Health Serv Res. 2008 Aug;43(4):1366-87. PMID: 18384361. Copyright © 2008 John Wiley and Sons. All rights reserved.



One of the things that we may not think about enough is how people react to and understand information differently? I have two slides showing some differences in the understanding of risk and benefit information by race and ethnicity. In this analysis we controlled for education so that effect shouldn't account for the differences that we see here. Essentially, we asked patients with breast cancer a couple of factual questions after they completed treatment. And we wanted them to answer, "true." Very few got the answer completely incorrect (the red bars), but there was a good percentage who didn't know the answer to the question (the green bar) and those responding in this way, were significantly more likely to be Latina patients and African-American patients. This is also disconcerting, raising the questions: What is happening? Is the information not being conveyed in a way that they understand it? Are they interpreting it differently? Are there communication issues on the part of the provider? We don't really know the answers but we would love to see everybody answering it correctly and we certainly don't want to see differences by race, ethnicity, or other factors.

## Understanding of Risk/Benefit

After which surgery is it more likely that a woman would need additional surgery?



The data presented are from a current ongoing study.

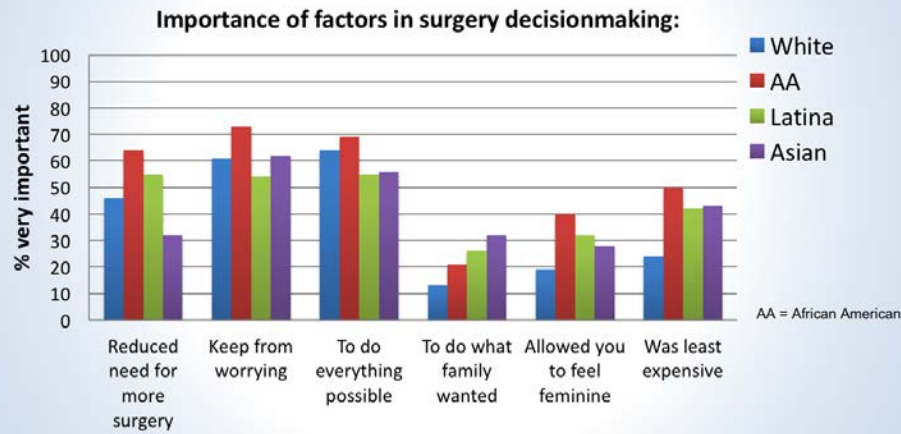
See also: Ramirez et al., 2013; Halbert et al., 2012



In a study which is still in the field now, we asked this question. “After which surgery is it more likely that a woman would need additional surgery?” The answer to that should be lumpectomy. What we see are the more white women get this answer correct than women in other racial and ethnic groups. And in this current study we also had Asian patients in our sample.



## Variation in Preferences for Care



The data presented are from a current ongoing study.



In variations in preferences for care, the differences in outcomes between racial, ethnic and cultural groups may be because patients prefer different things. In this study we asked patients, after they had completed their breast cancer treatment, "How important were these factors to you when you were making your decision, at the time you were making your decision?" This figure shows that there is a lot of variation across racial and ethnic groups. Pointing us to the thoughts that if providers don't know these things before going into the treatment decision-making process, then it's possible that they will miss an opportunity to inform a patient, to engage a family member, to help educate them about the cost of care, and as a result patients will be making decisions without these very important values being considered.

## Variation in Preferences

|                        |  |
|------------------------|--|
| Smith et al., 2008     | When compared with white patients, black and Hispanic patients were significantly less likely to have an advanced care plan based on preferences (minorities more likely to want to prolong life and to consider religion very important). |
| Hawley et al., 2008    | Racial/ethnic differences were found in preferences for colorectal cancer screening test attributes (black patients more often preferred higher accuracy).   |
| Showalter et al., 2015 | Variations were found in patients' preferences for prostate cancer treatment.  |

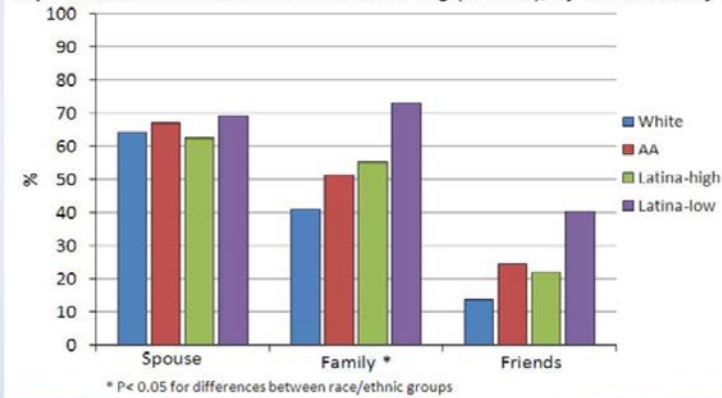
Smith A, McCarthy E, Paulk E, et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *J Clin Oncol*. 2008 Sep; 26(25):4131-7. PMID: 18757326.  
Hawley S, Volk R, Krishnamurthy P, et al. Preferences for colorectal cancer screening among racially/ethnically diverse primary care patients. *Med Care*. 2008 Sep;46(9 Suppl 1):S10-6. PMID: 18725820.  
Showalter T, Mishra M, Bridges J. Factors that influence patient preferences for prostate cancer management options: A systematic review. *Patient Prefer Adherence*. 2015 Jul;9:899-911. PMID: 26170640.



Other studies have shown variation in preferences in different racial and ethnic groups, so I think it's just something that we really need to be aware of, and to think of ways to help providers elicit those preferences so that those conversations can be more rewarding.

## Role of Family/Others

Figure 1. Proportion of breast cancer patients reporting others were very important in their treatment decision making (N=2268), by race/ethnicity



Family and friends play different roles in the healthcare process in different cultural groups. We were able to examine this in our breast cancer sample. When we asked patients, "How important were these people when you were making your initial treatment decision?" The less acculturated Latina patients indicated a higher level of importance for family and friends relative to other racial/ethnic groups.

## Role of Family/Others

|                     |   |
|---------------------|---|
| Maly et al., 2006   | When compared with African-American and white women, Latina women were more likely to identify a family member as the final treatment decisionmaker.    |
| Lillie et al., 2014 | Hispanic/Latino partners of breast cancer survivors report the most decision involvement but also the highest decision regret.                          |
| Hobbs et al., 2015  | Most patients with colorectal cancer involve family members in treatment decisionmaking, particularly non-English-speaking Asian and Hispanic patients. |

Maly R, Umezawa Y, Ratliff C, et al. Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients. *Cancer*. 2006 Feb;106(4):957-65. PMID: 16402372.  
Lillie SE, Janz NK, Friese CR, et al. Racial and ethnic variation in partner perspectives about the breast cancer treatment decision-making experience. *Oncol Nurs Forum*. 2014 Jan;41(1):13-20. PMID: 24368235.  
Hobbs GS, Landrum MB, Arora NK, et al. The role of families in decisions regarding cancer treatments. *Cancer*. 2015 Apr;121(7):1079-87. PMID: 25708952.



Other studies have also shown this, too.

## Community

|                      |  |
|----------------------|--|
| Preston et al., 2014 | Cancer councils may be a way to involve community members in strategizing.                               |
| Kent et al., 2015    | National Cancer Oncology Research Program (NCORP) initiatives may improve access and reduce disparities. |

Preston M, Mays G, Jones R, et al. Reducing cancer disparities through community engagement in policy development: the role of cancer councils. *J Health Care Poor Underserved*. 2014 Feb;25(1 Suppl):139-50. PMID: 24583493.  
Kent E, Mitchell, Castro K, et al. Cancer care delivery research: building the evidence base to support practice change in community oncology. *J Clin Oncol*. 2015 Aug;33(24):2705-11. PMID: 26195715.



The community and the role of advocacy groups in the community may vary in different cultural areas and geographic areas. These are just a couple of articles that have focused on ways that we can disseminate cancer care in different communities and increase access and patient engagement treatment decision making..

## Provider Factors

|                             |  |
|-----------------------------|--|
| George, 2012                | Providers need to be aware of different (and potentially unconventional) beliefs among their patient populations that may influence use of treatment; they also need to ensure effective communication to address these beliefs. |
| Mejia de Grubb et al., 2015 | Primary care physician-residents reported it was difficult to interact with individuals from different cultures about cancer prevention and control because of perceived differences in attitudes/beliefs.                       |

George M. Health beliefs, treatment preferences and complementary and alternative medicine for asthma, smoking and lung cancer self management in diverse Black communities. *Patient Educ Couns.* 2012 Dec;89(3):489-500. PMID: 22683293.  
Mejia de Grubb M, Kilbourne B, Zoorob R, et al. Resident Physicians and Cancer Health Disparities: a Survey of Attitudes, Knowledge, and Practice. *J Cancer Educ.* 2015 May 7 [Epub ahead of print]. PMID: 25943900.



A couple of papers have highlighted that providers need to be aware of different beliefs among their patient populations that may influence their use of treatment. In the second study by Mejia de Grubb, primary care physician residents reported it was difficult to interact with individuals from different cultures because of perceived differences in attitudes and beliefs.

## Additional Considerations

- **Interventions may not be developed with racial/ethnic or cultural differences in mind**
- **Individuals from different backgrounds may respond to interventions differently.**



We should remember that interventions may not be developed with racial, ethnic or cultural differences in mind, and that individuals from different backgrounds may respond to interventions differently. So if we're thinking about interventions to improve engagement and share decision making, I think these are important points to remember.

## Intervention Response

|                       |   |
|-----------------------|---|
| Kreuter et al., 2010  | Narratives effective in cultural subgroups for increasing adherence to cancer prevention              |
| Myers et al., 2014    | Navigation tailored to patient preferences for cancer screening had positive impact among AA's        |
| Resnicow et al., 2014 | Communication style preference moderates impact of tailoring on cancer screening adherence among AA's |

Kreuter MW, Holmes K, Alcaraz K, et al. Comparing narrative and informational videos to increase mammography in low-income African American women. *Patient Educ Couns.* 2010 Dec;81 Suppl:S6-14. PMID: 21071167.

Myers RE, Sifri R, Daskalakis C, et al. Increasing Colon Cancer Screening in Primary Care Among African Americans. *Journal National Cancer Institute.* 2014; 106(12)..

Resnicow K, Zhou Y, Hawley S, et al. Communication preference moderates the effect of a tailored intervention to increase colorectal cancer screening among African Americans. *Patient Educ Couns.* 2014 Dec;97(3):370-5. PMID: 25224317.



Matt Kreuter and his group has done a lot of work in putting narratives into interventions, which is one way to overcome some of these challenges. Myers is showing navigation tailoring works differently in different racial and ethnic groups. Work by Resnicow has shown that communication style preference is important.



## What Is Needed

- Awareness of differences in belief systems, the existence of real/perceived discrimination and lack of trust in health system
- More work to understand how culture shapes preferences
- Novel methods to convey risk/benefit information to those from different cultural backgrounds
- Involvement of family and friends needs to be considered (potential missed opportunity)
- Innovations in interventions to use tailoring to engage patients from different cultural backgrounds
- Ways to measure/assess “culture” beyond race/ethnicity



What's needed I think: awareness of differences in belief systems and the existence of real and perceived discrimination, for example, understanding that there is a lack of trust in the health system. More work is needed to understand how culture shapes preferences and more novel methods are needed to convey risk and benefit information to those from different cultural backgrounds. Involvement of family and friends needs to be considered; I think in some cases, this may be a real missed opportunity to improve engagement and shared decision-making. Innovations and interventions to use tailoring has been shown to engage patients from different cultural backgrounds. Finally, we need then ways to measure and assess culture that go beyond race/ethnicity. We need to be thinking about all of these issues more broadly.

## Cultural Competence in Medicine

- Consider the role of providers
- One way = improve cultural competency:

“Using the foundations of narrative medicine to better understand the patient's story and integrate what is important to them into decisions about their health care.”

—Betancourt et al., Health Affairs, 2005

Betancourt J, Green A, Carillo E, et al. Cultural competence and health care disparities: key perspectives and trends. Health Aff (Millwood) 2005 Mar-Apr; 24(2):499-505. PMID: 15757936.



To conclude, the idea of cultural competence in medicine was introduced in the '90s. It got a lot of attention, but we haven't heard much about it recently. We've been focusing on patient-centered care and shared decision-making, but I think they really go together, and if we can remind ourselves of the importance of these issues when delivering care and include cultural issues in our training, we may see some positive outcomes in terms of shared decision-making.

## Improving Outcomes for Patients

### ■ Brach et al, 2000: Can Cultural Competence Reduce Health Disparities?

- Training needs: Interpreter services, training, inclusion of family members, use of community workers, immersion in culture
- Leads to: increased understanding of how culture influences behavior → Improved communication, increased trust, increased knowledge of treatment options
- Fosters: Shared Decision Making Shared Decision Making
- Results in: Better outcomes for patients (better health status, functioning and increased satisfaction)

Brach C, Fraser I. Can cultural competence reduce health disparities? A review and conceptual framework. Med Care Res Rev. 2000; 57 Suppl 1:181-217. PMID: 12938253.



Brach has a framework in a paper published in 2000 that outlines what we need and how that's going to result in better outcomes for patients. It shows what we need on the training side, how that will lead to increased understanding of cultural issues, how it will foster shared decision-making and how it will result in better outcomes for patients.

- **“The delivery of culturally adapted risk information is needed to increase and ensure Latinas' understanding of breast cancer genetic testing during their decision-making processes. Key Latino values-religiosity, importance of family and the influential role of health care providers in health decisions-should also be considered when designing interventions targeting this specific group. Further research is needed to identify effective ways to communicate genetic risk susceptibility information to Latinas to help them make informed testing decisions.”**

- Chalela et al., 2012 (emphasis added)

Chalela P, Pagán JA, Su D, et al. Breast cancer genetic testing awareness, attitudes and intentions of Latinas living along the US–Mexico border: a qualitative study. *J Community Med Health Educ.* 2012;2. PMID: 25473590.



This is a quote from a paper by Chalela and colleagues published in 2012 that focused on BRCA testing. The quote highlights the importance of acknowledging the role of family when conveying risk and benefit and in shared decision-making. Such cultural issues and challenges are relevant not just to this issue but to all issues and all conditions. We can really pay attention cultural -- religiosity, the importance of family -- design interventions targeting these groups. Thank you.