

## **Decision Support in Rural, Underserved North Coast Counties**

Jeff Belkora, PhD

Director of Decision Services, UCSF

Sara O'Donnell

Executive Director, Cancer Resource Center of Mendocino County

Julie Ohnemus, MD

Medical Director, Humboldt Community Breast Health Project

Lauren Franklin

Study Coordinator, MHU Collaborative

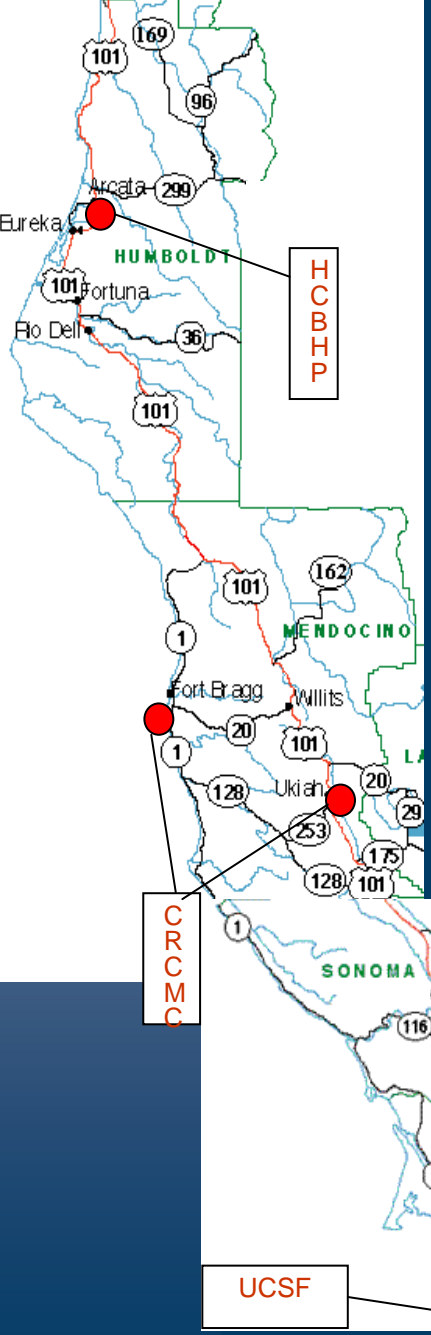
12 cultural advisors, 12 breast cancer survivors, 12 past clients

24 advisory board members, 6+ resource center staff

California Breast Cancer Research Program - Symposium

September 10, 2005

# Our communities



Indicator	Mendocino – 2000	Humboldt – 2000
Pop. (area sq mi.; density)	86,265 (3,510; 24.6)	126,518 (3,536; 35.4)
Poverty	15.9% below the poverty line	19.5% below the poverty line
2004 expected BrCas	60	95
Race/ethnicity	17% Latino 5% Native American	6% Latino 6% Native American
Frontiers (density <11/m <sup>2</sup> )	4 designated frontiers	2 designated frontiers

# Our resource centers

Resource Center	2004	
	New clients	Breast clients
CRCMC	250	88
HCBHP	197	169

## Outline

- Intervention and research design - Jeff
- Preliminary findings on telephone delivery - Sara
- Preliminary findings on cultural competence - Julie
- Overall lessons about the research partnership - All

## Background

- Topic is support for patients as they make breast decisions
- Decision support starts with helping patients formulate questions
  - Consultation Planning (CP): service to help patients make a list of questions
  - CP found effective at UCSF, Stanford
- Since 1998, PIs have adapted CP for North Coast
- Number of Consultation Plans has grown steadily
  - 2001-2004: 21, 43, 132, 145
- Potential demand for CP in counties is 800/year for breast alone
  - Based on number of biopsies for new cancers and recurrences
- CP could also be expanded in other health conditions
- Community challenged us to provide CP for all, including underserved
  - Rural, isolated
  - Spanish-speaking Latinas
  - Native American Indians

Situation	Questions or concerns about your situation? your diagnosis? test reports? pathology report?
Choices	Questions or concerns about which options to consider? What options have you heard about? treatment options? tests? second opinions? clinical trials? complementary therapies? new treatments? most aggressive treatments? least aggressive? middle ground? ...remedies for side effects?
Objectives	Goals? for your upcoming consultation? for quality of life? for length of life? What's going on that might affect your choices? What do you hope to continue doing in your life (e.g. hobbies, work, activities, body image, sexuality, child-rearing, etc.)? What are the important things in your life you wish to protect? What else do you hope to achieve? What would be your ideal treatment? Other hopes or fears about the future? Any thoughts or feelings you're not talking about with anyone?
People	Who are the key people you want to include in making decisions? ... anyone to be excluded? Who should have visibility (kept informed), a voice (seek their input), a vote (make a decision with you)? How do you want to work with this doctor? ... other doctors? Are you getting the support you need? Can you go to family or friends for advice or support?
Evaluation Process	How will you figure out which options best meet your goals? What is your timeline for making decisions that need to be made? How much time you can safely take? How far along are you in a decision? (not thinking about it, figuring it out, done) Which way are you leaning? Are you making this decision scientifically (looking to data)? socially (looking to what other people would do)? spiritually (looking to God)? soulfully (looking inside)? somatically (listening to body signals?) combination?
Data	What information could help you figure out what to do? Questions about: ...your prognosis with no more treatment? Numbers (60% 10-year survival) or words (more likely than not)? ...how your choices will affect your survival? Survival rates for patients like you? Recurrence rates? ...how your choices will affect your quality of life? Likelihood of side effects? ...best-case scenario, worst case, most likely (in terms of survival, quality of life) for each treatment option? ...how your choices might affect your other health issues or medications (e.g. treatment interactions)? ...what's involved in doing treatment, e.g. timing, frequency, duration, location, costs of treatments? ...the next steps in your plan of care? ...what needs to occur for your treatment to be carried out smoothly? ... who does what, when? ...what resources can help you overcome any barriers to treatment and recovery? ...insurance? ... logistical?

**CP Prompts**

Situation	<p>Margins on my lab report: What is the “inferior margin”?</p> <p>My impression is that in situ means pre-cancer, but my path report says I have invasive cancer and in situ?</p> <p>Why did I only have two nodes removed? Does that mean that every node beyond those two nodes is clear?</p> <p>So according to the pathology report, has my cancer been totally removed?</p> <p>Ultrasound showed the size of my cancer as 1.4cm, but the report says 2.1cm. Why the discrepancy?</p> <p>How aggressive, how fast growing is my cancer? What is the stage of my cancer?</p> <p>Why am I estrogen receptor positive 3+? Why do I have so much estrogen? I’ve never taken hormone replacement therapy or anything else.</p> <p>Does cancer travel primarily through the lymph nodes?</p>
Choices	<p>Because of the small 1mm margin, could more surgery be beneficial?</p> <p>Radiation? Can I just give radiation a try? Can I stop in the middle? How many times a week?</p> <p>Tamoxifen? Chemotherapy? How often would I need chemotherapy? How is chemotherapy administered?</p> <p>What do I do for cancer screening from here on out?</p> <p>Are there tests for fast growing cancer? S-phase fraction test and Ki-67 - have a tissue - Books said they are not reliable (Dr. Susan Love’s breast book)</p> <p>I have had a rash on my chest since the surgery. Any advice on what to do for that?</p>
Objectives	<p>Quality of life is important, but necessarily quantifiable.</p> <p>I would like to live until June - see my grandchildren graduate from high school.</p> <p>I want to feel well enough to enjoy my family.</p> <p>Surgery to me seems easier to bounce back from than radiation or chemotherapy.</p>
People	<p>I would like Dr. Oncologist to lay out the options for me to consider.</p>
Evaluation Process	<p>I will make the decisions myself, with input from my doctors.</p> <p>How are urgent are the decisions?</p> <p>I consider chemo to be a poison to the body. I think if I were 40, I might consider it, but at my age, it will take more to convince me to take it, though I will take it if I have to.</p>
Data	<p>If I don’t do more treatment, where will the cancer go if it travels? Does it always go to liver?</p> <p>What is the risk of local recurrence without radiation? Does it really work? The stats I’ve seen make it seem like it doesn’t make much of a difference.</p> <p>What are the side effects of Tamoxifen and chemotherapy treatments?</p>

## Research

- Pilot study goal is to adapt CP for broader distribution
  - Culturally competent delivery to Latinas, Native Americans
  - Telephone delivery to rural underserved
- Approach is to get feedback on CP from key stakeholders
  - Feasibility Phase: do cultural advisers endorse CP and tele-CP? Modifications?
  - Acceptability Phase: do diverse breast patients accept CP intervention? Modifications?
  - Viability Phase: were past recipients of tele-CP satisfied with telephone delivery? Modifications?
- Method is Critical Incident Technique to document requirements, specify design changes.
- Full study will look at impact of modified CP

## Outline

- Background and research design - Jeff
- Preliminary findings on telephone delivery - Sara
- Preliminary findings on cultural competence - Julie
- Overall lessons about the research partnership - All

## ***Tele-CP ruled out early for Native American Indian (NAI) and Latino Communities***

- Feasibility Phase - Cultural Adviser interview findings included suggestion that doing Consultation Planning over the telephone may not be appropriate for these communities
- “[They] are not comfortable with the telephone in general. They prefer person-to-person under any circumstances, but especially if discussing something where they are less familiar with the issues and/or it is a crucial medical condition.”

## ***Tele-CP appears viable for rural, isolated clients***

- Tele-CP is viewed as effective by clients and providers
- Clients are satisfied with Tele-CP
- Tele-CP has several benefits
- Tele-CP has few disadvantages
- There are things that can be done to mitigate the disadvantages

## ***Tele-CP is seen as effective by clients and providers***

- Interviews with past recipients and providers of Tele-CP in process (completed 9 as of 9/1/05)
- All responded "yes" when asked if she felt that the Tele-CP had been effective in helping her prepare to meet with her physician
- Recipients rated Tele-CP high on the Satisfaction with Visit Preparation (SVP) scale
- Many things considered effective aspects of in-person CP are also considered effective over the telephone

## ***Tele-CP has several benefits***

- **Timing**
  - Tele-CP is often available at the last minute
  - No Distance Barrier
  - Some clients live close to an hour away from the resource center where CP is offered
- **Travel**
  - Clients sometimes lack transportation even for shorter distances
- **Convenience**
  - Some clients do not feel well enough to visit the resource center
  - Others noted the convenience of not needing to get dressed, drive, find parking

## ***Disadvantages of doing CP over the telephone***

- Most of the study participants found no disadvantages to doing the CP over the telephone
- A few felt that they might have been more comfortable meeting face-to-face
- Provider has less control over the environment
- Lack of control over client privacy
- Interruptions on the client's end

## Qualifications and Caveats

- Two of the Tele-CP recipients interviewed had received in-person CP prior to the Tele-CP
- One of the Tele-CP recipients visited the resource center and met the CPer prior to the Tele-CP

## Recommended Modifications

- Creating the Time
  - Contracting with client includes setting aside sufficient time
- Creating the Space
  - Talk with the client about setting aside a private space
- Building Rapport
  - Take time at beginning of phone call to chat with the client
  - Explain what is going to take place

## Outline

- Background and research design - Jeff
- Preliminary findings on telephone delivery - Sara
- Preliminary findings on cultural competence - Julie
- Overall lessons about the research partnership - All

# ***In-person CP appears feasible and acceptable to Latina / Native American Breast Cancer Survivors***

## **IT WORKS!**

1. Holistic - Fits with the NAI value system
2. "Giving Voice" (Latina Cultural Advisor)
  - Gives the patient the opportunity to say things that someone else may not be letting them say
3. Preparation / greater awareness of other options

"Supports the whole person"  
NAI Cultural Advisor

"Letting them tell us what's going on - Letting the participants frame their story"

NAI Cultural Advisor

## ***Modifications? Need to emphasize...***

- Do not need to have medical knowledge to have a CP
- No physical exam involved in the CP session.
- Make sure the client knows the CPer is not in a hurry, has plenty of time to share
- Preferable if the CPer is from their own culture
- Relationship building is essential -- CPer sharing their story
- Greater awareness of body language and the cultures' discomfort with technical settings (e.g. computer)
- Gender - prefer female
- Focus on healing

## **Cultural Differences - Latina**

- Translation
  - Language barrier “hinders patient openness”
  - How wording of prompts translate
- Western Medicine - process is alien to them
- FolkWays
  - Views disease process differently
  - Beliefs not shared with the provider

“Latino folk medicine believes that illness is caused by an imbalance of hot and cold principles. Diseases are classified as hot or cold. For example, cancer is a hot condition. The goal of treatment is to restore balance. Hot conditions are treated with cold remedies, and cold conditions are treated with hot remedies. Latina women are hesitant to do radiation (hot treatment) for cancer.”

## **Cultural Differences – Native American Indian**

- Literacy Level
- Distrust of “white man’s medicine” - affects adherence
- Western focus on specialization is powerful, but is disconnected from a holistic framework
- Provider responsibility for cultural sensitivity - lack of leads to lack of trust
- Trust is built over time

“If they do not know you,  
they will not be as honest”

## Theme: Building Rapport

### LATINA

- "Chit-chat"
- Respect for the family authority figure
- Respect supercedes disclosure
- Not culturally appropriate to challenge physician
  - OK for third party to confront the physician
  - Voice agreement with physician

### NAI

- Silence - "Be with silence. It lets you think about what your goals are."
- Be comfortable so the patient can "just talk" -- "You can learn more by just letting the patient talk then by asking rote questions"
- Call patient by name
- Ask about the patient's family
- Build a relationship over time
  - One-time contact seems insincere
  - Lack of time leads to no patient feedback and questions

## **Theme: Decision Making - Latinas**

- Uncomfortable as the center of attention - vulnerable position
- Take care of everybody else first
- Not ok to have needs and wants
  - Complaining is not acceptable
- Faith - It is God's decision
  - "God will take care of it" and "what will happen will happen".
- Discrepancy between what thinking and what telling the doctor
  - May not bring something up if not asked directly

"A traditional Hispanic woman would not have a lot of authority or rights and would expect that her needs come last after everybody else has been taken care of. Even vocalizing needs and desires and preferences is hard for her to do. It is important to clarify with her that it is ok to have needs and preferences."

## **Theme: Decision Making – Latinas (cont'd)**

- “La familia” process -- the patient is not primary decision-maker
- Often Male decision-maker
  - “behind the scenes”
- Important to address in CP
  - who is making the decisions?

“In our culture, we let everybody else because we were told since we were kids that when you are sick you can't make any decisions. So you let somebody else do it.”

“Once you leave, the patient will go to the authority and do whatever she or he said.”

“Encourage both to go together so the authority figure listens to the options from the health professional, he or she could help the patient to make the best decision.

## **Decision Making – Native American Indian**

- Matriarchal culture / female authority
- Fear - Large barrier
- Inability to act - "What if?"
- "Nobody wants to talk about death"



Potawat Indian Health Village, Arcata, California

## Outline

- Background and research design - Jeff
- Preliminary findings on telephone delivery - Sara
- Preliminary findings on cultural competence - Julie
- Overall lessons about the research partnership - All

## ***Lessons learned about community-based research***

### The relationship “domino effect”

- The “spine” of the CP is all about “relationship building” => the relationship of the CPers with the tool; the relationship of the CPers with the Client; the relationship with the Client to the Doctor; the relationship of the Doctors with the tool
- CPer & CP needs to commence building the trust and relationship for the medical provider