

Implementing Decision Support for Diverse, Rural Patients in Medically Underserved Areas

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Study Collaborators

- UCSF Decision Services
 - Mission: Create, deliver and evaluate decision support
- Cancer Resource Center of Mendocino County (CRCMC)
 - Mission: Improve the quality of life for those faced with cancer
- Humboldt Community Breast Health Project (HCBHP)
 - Mission: Support people dealing with breast or gynecologic cancer
- University of Ottawa, Canada
 - Prof. Stacey provided expertise on telephone decision support

Study Setting

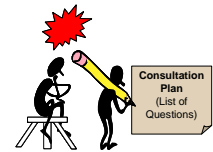
Mendocino and Humboldt are diverse, rural medically underserved counties on the North Coast of California

Indicator	Mendocino – 2000	Humboldt – 2000
Pop. (area sq mi.; density)	86,265 (3,510; 24.6)	126,518 (3,536; 35.4)
Below poverty line	16%	20%
2004 expected BrCas (N)	60	95
Race/ethnicity	17% Latino 5% Native American	6% Latino 6% Native American
Frontiers (density < 11/m ²)	4	2

Driving distances are long: approximately 2 hours from resource centers to outer edges of counties

Study Intervention: Consultation Planning (CP)

- Visit preparation intervention for patients (Ref 1)
 - Developed and implemented at urban academic medical centers
- Helps patients create a list of questions for their doctors
- Prompt sheet administered by a trained CP Provider (CPer)
- Compare with other work on prompt sheets, pro formas
 - e.g. Brown (Ref. 2), Butow (Ref 3), Wells (Ref 4)



CP Prompts: Questions and Concerns about...?

Situation	Diagnosis? Test reports? Pathology report? Anything unusual to note about your situation?
Choices	Treatment options? No treatment? Tests? Second opinions? Clinical trials? Complementary therapies? New treatments? Most aggressive treatments? Least aggressive? Middle ground? Remedies for side effects? What to stop doing? What to start? Future decisions to anticipate? Past decisions to revisit?
Objectives	Goals for consultation? Treatment? Quality of life (e.g. existing hobbies, work, activities, body image, sexuality, child-rearing, etc.)? Recurrence? Survival? Numbers (e.g. 60% ten-year survival rate) or words (e.g. more likely than not to survive)? Learning preference: visual or auditory or other type of learner? Hopes or fears about the future? Unspoken thoughts or feelings?
People	Who do you want to have a voice in your decisions (i.e., seek their input)? A vote (involve them in making the decision)? Visibility (keep them informed)? Anyone to exclude? Specifically, how do you want your doctor involved? Other doctors? Other people (e.g. companions)? Where else to go for advice or support?
Evaluation	Baseline prognosis (prognosis with no further treatment)? How choices will affect survival, recurrence (e.g. rates for patients like you)? How choices will affect quality of life? Likelihood of complications, short and long-term side effects? Best-case scenario, worst case, most likely (in terms of survival, quality of life) for each choice? Impact on other health issues or medications (e.g. treatment interactions)? What's involved in doing treatment, e.g. timing, frequency, duration, location, costs of treatments?
Decisions	Which options are you leaning towards? Why? Next steps in plan of care? Who does what, when? What resources can help overcome any barriers to treatment and recovery? Insurance issues? Logistical issues?

Example CP from Mendocino patient

Situation	Is the size of the tumor significant? What does high-grade invasive ductal carcinoma mean? Please explain Her2/neu overexpression. I am ER/PR positive. What does that mean?
Choices	What treatment do you recommend for me?
Objectives	I want to do everything I can to beat this and not have a recurrence.
People	I will make my decision about treatment with my husband. He is very supportive. I also want Dr. Primary Care to be kept on the loop.
Evaluation	What is my prognosis with no further treatment? How does doing the treatment you recommend change that? What are the side effects? Is there anything else I need to do before starting treatment? How long does it take to feel normal again after treatment is over?
Decisions	How much time can I safely take to make a decision? My husband and I had planned a trip to Canada before all this happened.

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Study Purpose and Questions

- Purpose
 - Adapt CP for broader use with rural, diverse breast cancer patients
 - Focus on needs of Latinas and Native Americans
 - Pilot study in preparation for larger randomized trial of CP vs. Tele-CP
- Questions
 - 1) CP endorsed by Latina & Native American cultural advisors?
 - 2) CP acceptable to Latina & Native American breast cancer survivors?
 - 3) CP acceptable when delivered by telephone (Tele-CP)?

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Methods

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Study Design, Data Collection & Analysis

- Purposively recruited subjects for Critical Incident Technique interviews
 - What is effective/ineffective about intervention? Responses coded into themes.
 - Specifically asked Latinas and Native Americans about viability of Tele-CP
- Satisfaction with Visit Preparation Scale (5-item) [Ref 1]
 - Compared median score with prior data for in-person CP
- Acceptability of Decision Aid Survey (9-item) [www.ohri.ca/decisionaid]
 - Compared proportions rating "useful" to acceptability threshold of >66%
- Practitioner Opinion Survey (14-item) [www.ohri.ca/decisionaid]
 - Compared calculated score to acceptability threshold of 48/60

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Summary Table of Methods

Aim	Participants	Data Collection
1) CP Endorsed?	15 cultural advisors	Interview
2) CP Acceptable?	12 breast cancer survivors	Simulated CP Interview Acceptability Survey
3) Tele-CP Acceptable?	10 Tele-CP clients	Interview Satisfaction Survey
	7 Tele-CP providers	Interview Pract. Opinion Survey

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Results

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Study Participants

- Aim 1: 6 Latina and 9 Native American Cultural Advisors
 - Physicians, nurses, outreach workers, translators, volunteers, administrators
 - Recruited from resource centers, Indian Health Services and Latino clinics
- Aim 2: 6 Latina and 6 Native American breast cancer survivors
 - Identified through networking and referrals from resource center staff
 - History of breast cancer (3 DCIS, 2 stage I, 1 stage II, 2 stage IV, 4 missing)
 - 6 months - 15 years post-diagnosis (median 3 years)
 - Included 2 monolingual Spanish speakers (CP with Spanish translator)
- Aim 3: Tele-CP participants
 - 10 recent recipients of Tele-CP from resource centers (white, non-Hispanic)
 - History of breast cancer or breast health concern (5 stage I or II, 5 missing)
 - 2 months - 22 months post Tele-CP experience (median 14 months)
 - Included 7 staff members who provided the Tele-CPs

Aim 1 Interview Themes (Cultural Advisors)

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- Supports the whole person
 - “CP is consistent with our mind/body/spirit approach to healing. Plus, it looks scientific so the doctors will go along with it!”
- Varied levels of patient involvement in decision making
 - “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.”
- Logistical barriers (translation, child-care, transportation)
 - “It is an all day commitment to come into town or to the clinic”

Aim 1 Results: CP Endorsed

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- Latina and Native American Cultural Advisors endorsed CP
- Specific recommendations incorporated into revised CP:
 - Provide medical interpretation for Spanish monolingual patients
 - Build rapport over time
 - Explain no physical exam involved
 - Make sure client knows there is no rush
 - Keep language simple
 - Ask about family involvement in decision making
 - Recruit CP Providers from Latino and Native American communities

Aim 2 Interview Themes (Survivors)

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- CP helps organize and clarify thoughts
 - “CP helped me to look at things more deliberately”
- Relationship with the CPer is important
 - “I began to feel more comfortable and open up when the CPer did not show judgment or shock about what I said.”
- Personal stories build trust and rapport
 - “CPer did not tell me about her experience with breast cancer and I was wondering about it the whole time”
- Facing the client and eye contact are important behaviors
 - “The CPer was using a computer and this felt uncomfortable to me”

Aim 2 Results: CP Culturally Acceptable

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- CP content, delivery, usefulness highly rated
 - 6/6 Latinas, 6/6 Native Americans rated CP prompts “good” or “excellent”
 - 5/6 Latinas, 5/6 Native Americans rated CP length “just right”
 - 6/6 Latinas, 6/6 Native Americans rated CP “useful”
- Suggested further modifications for CP:
 - Make the space more child-friendly
 - Share more stories of personal experience
 - Make sure the client knows the service is confidential
- Consensus that Tele-CP was “worth studying”
 - Telephone could be barrier to rapport, but more convenient

Aim 3 Interview Themes (Tele-CP)

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- Timing flexibility and convenience
 - “The Tele-CP accommodated my hectic schedule”
 - “Allowed me to be at home in comfortable surroundings”
- No transportation or distance barrier
 - “I avoided a long driving time by doing CP over phone.”
- Lack of visual contact
 - “CPer told me when she was writing and read it back to me”
- Less control over the environment
 - “I was distracted by children fighting in the house.”
- Less control over client privacy
 - “People think they can interrupt when you are on the phone”

Aim 3 Results: Tele-CP Acceptable

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- Past Tele-CP recipients satisfied
 - Median 10/10 on Satisfaction with Visit Preparation Scale
 - Similar to results from study of In-Person CP in this setting [Ref 1]
- Tele-CP Providers satisfied
 - Median 51/60 on Practitioner Opinion Scale
 - Exceeded our threshold (48/60) for acceptability
- Recommended Modifications
 - Contract with client to set aside an appropriate block of time
 - Send advance materials (e.g. prompt sheet, photos)
 - Encourage the client to find a private, quiet space
 - Build rapport early in the call

Conclusions

Conclusions

- CP acceptable for Latina and Native Americans in pilot study
- CP acceptable for delivery by telephone (Tele-CP)
- Tele-CP viable for further study in these counties
 - Currently starting non-inferiority trial of Tele-CP and CP
 - Primary outcome: decision self-efficacy
 - Includes outreach and recruitment for Latinas and Native Americans

Resource Center organizational outcomes

- Research
 - Awarded funding for randomized trial of Tele-CP vs. In-Person CP
- Programs
 - Trained 25 medical interpreters
 - Increased community outreach to Latinas and Native Americans
- New CP Techniques
 - Updated CP training manual to reflect study findings
 - E.g. mailing advance packet of materials to Tele-CP clients
- New Tele-CP Tools
 - E.g. telephone headsets for Tele-CP providers

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- Mendocino Coast Clinics
- Nuestra Casa
- Ottawa Health Research Institute (www.ohri.ca/decisionaid)
 - Acceptability of Decision Aid (© O'Connor, 2000)
 - Practitioner Opinion Survey (© Graham, 1996)

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