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SUMMIT

Difficult Conversations
Role of a Nurse Navigator

Cynthia (Cindi) Cantril, RN, MPH, OCN, CBCN
Director of Cancer Support Services and Patient Navigation
Sutter Pacific Medical Foundation
Santa Rosa, CA
cantric@sutterhealth.org

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Historical Perspectives

“ It may be that no other disease demands of the nurse so much sympathetic understanding of human relationships as well as knowledge of the disease itself. Probably no other illness requires such wise guidance in building morale to help the patient and his family meet their problems.”

- A Cancer Source Book for Nurses, American Cancer Society, 1963


You never know
how strong you are
until being strong
is the only choice
you have.

Objectives

- Describe the critical communication points in a cancer care continuum: Pre-diagnosis, end of treatment, end of life
- Discuss the nurse navigator role is assisting patients in hearing “bad news”
- Review what patients want from their perspective
- Examine multidisciplinary support and utilization

A Personal Journey – Three Case Studies

- Early in my career – Bill – being aware of promise you cannot keep
- Mid career - a surgeon’s daughter
- A cancer journey from diagnosis to end of life - Heidi

Pre-diagnosis

Factors to Consider

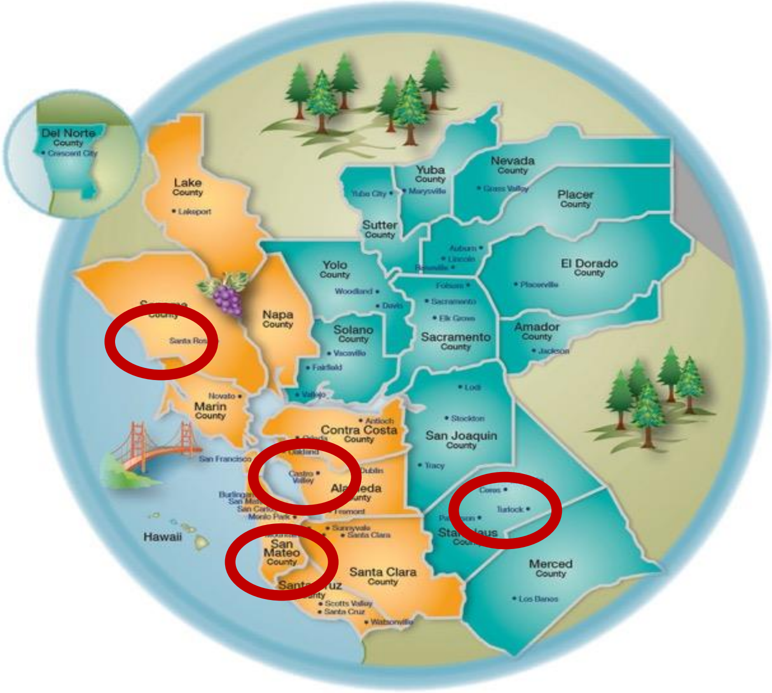
- What do I need to know?
- How will this impact the patient as I currently see them?
- What can I do to prepare them?
- What comfort can I give?
- Provide next steps and visit

Diagnosis Disclosure

- Literature review
  - Magro et al (2016), *"Diagnosis Disclosure Process in Patient With Malignant Brain Tumors".*
  - Morse et al (2014), *"Awaiting a diagnosis of breast cancer: Strategies of enduring for preserving self".*
  - Baile et al (2000), *"SPIKES- A six-step protocol for delivering bad news: Application to the patient with cancer".*
- Breaking bad news, what patients prefer
  - Burklin, Y. et al (2018), *"Management of Emotionally Challenging Responses of Hospitalized Patients With Cancer".*
  - Shim, E.J., et al (2016), *"Tailoring Communication to the Evolving Needs of Patients Throughout the Cancer Care Trajectory: A Qualitative Exploration With Breast Cancer Patients".*

The Patient Experience Survey

Sent to 517 patients diagnosed with breast cancer from Oct 2015-Jul 2016 in four different geographic areas; received 199 completed surveys; excellent response rate (38%).



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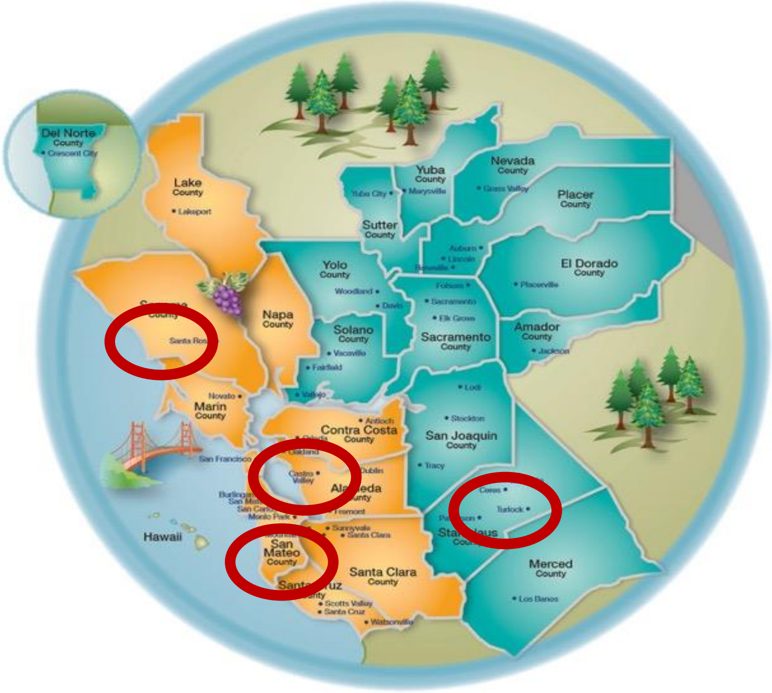
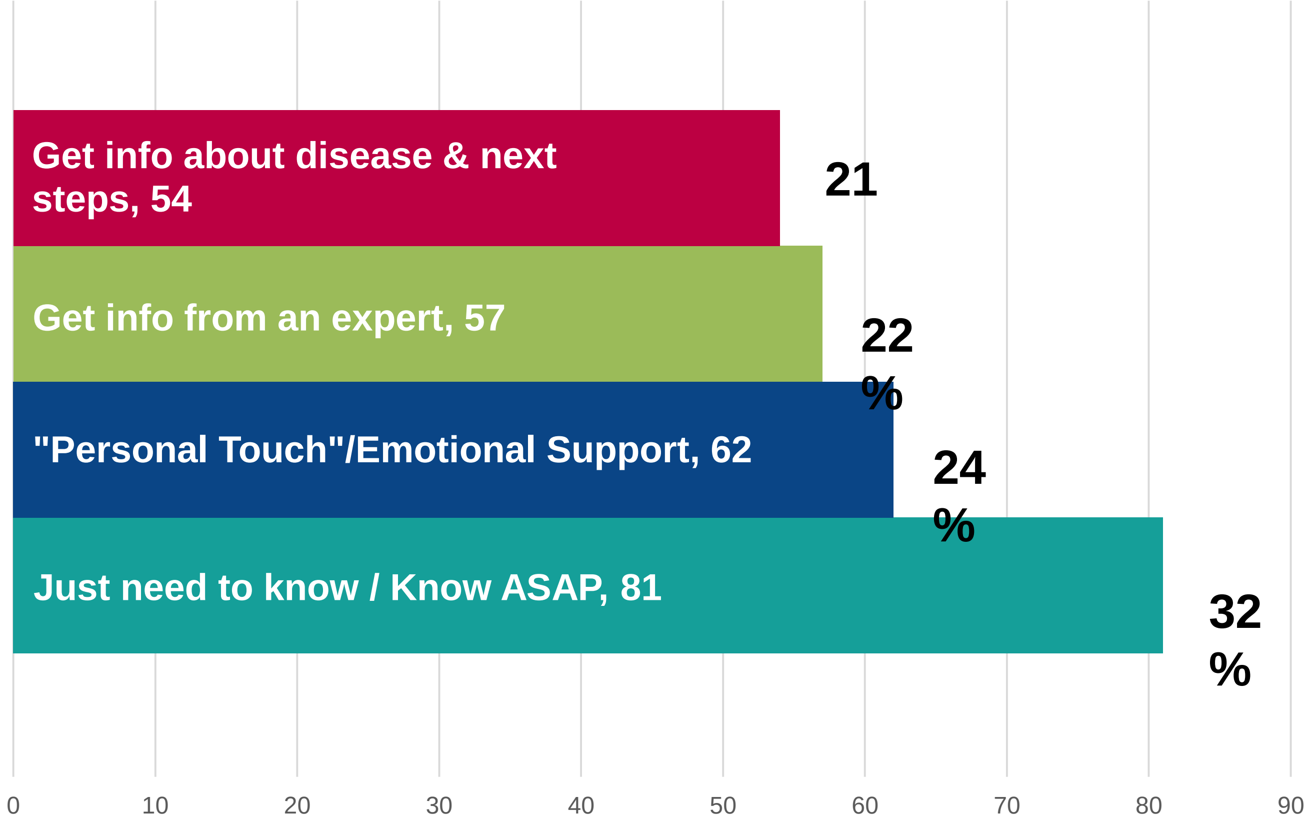


Where patients have reported being told their breast cancer diagnosis

A Study on the Effect of Nurse Navigation

SUTTER HEALTH NAVIGATION MODELS	
Location A	Location B
Navigator reaches out to patient *after* patient has received breast cancer diagnosis (i.e., after imaging, biopsy, waiting for path, hearing news, receiving referral)	Navigator becomes involved *at time of* suspicious finding (i.e., when patient receives imaging at Breast Center)
PCP informs patient of diagnosis, significant variability of time	*Nurse Navigator* informs patient of pathology results within 3 days
Patient referral to their initial oncology MD *made by* PCP	Patient referral to their initial oncology MD *facilitated by Nurse Navigator*

What patients value when they are told their breast cancer diagnosis:



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Statistical Analysis

- Those people who heard in person were more satisfied than those who heard on the phone (p = .006)
- Nurse Navigator informing patients most likely to give what patients valued: right amount of time, resources, emotional and educational support…*more than other types providers* (PCP, radiologists)
- People who value "personal touch" were more likely prefer *in person*; people who value "just want to know" were more likely to prefer *on the phone*; people who "want info about disease next steps" were more likely to prefer *in person*
- Additional analysis in progress…..

SPIKES PROTOCOL

1) Setting up – reviewing the plan, privacy, significant others, sit down, make connection, manage time
2) Perception – before you tell, ask
3) Invitation – how much information do they want? Can absorb?
4) Knowledge – "I am sorry to tell you….."
5) Emotions – observe and identify
6) Strategy and Summary

Baile, et al (2000)

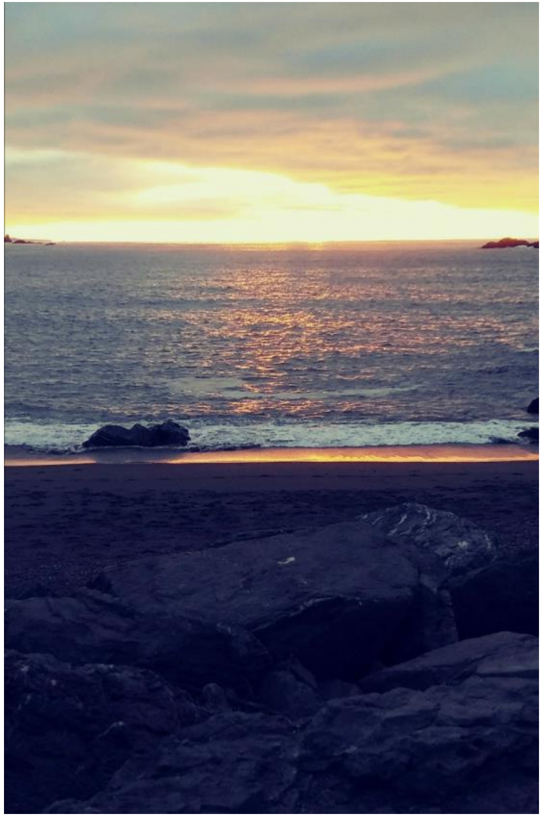
Turning Points

- End of Treatment
- Recurrence
- Palliative Care
- End of Life

After Treatment, What Next?

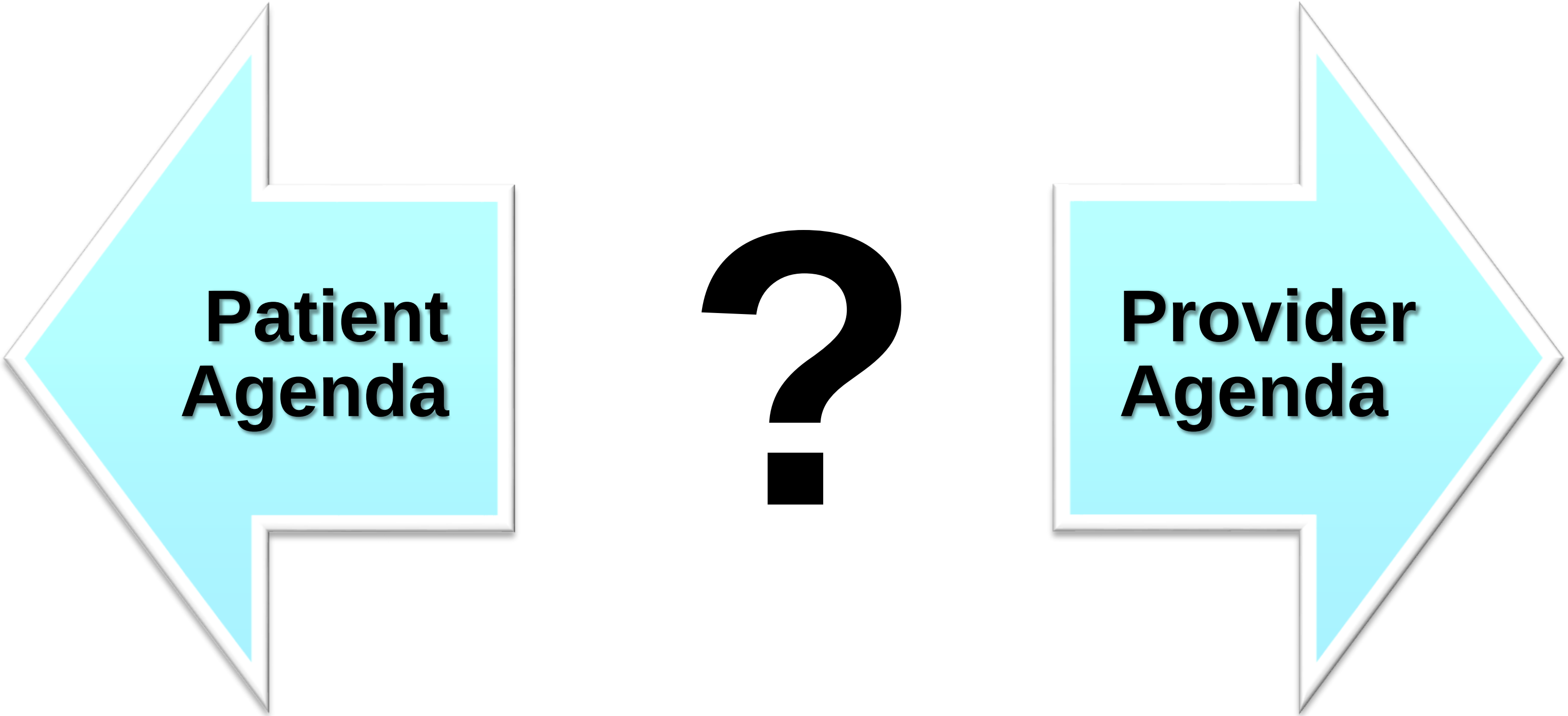
- How to be helpful, hopeful, and move forward

- Decreasing anxiety in the patient and seizing the moment



"An observational cohort study of 120 terminally ill patients, 99% identified a sense of hope as their main existential concern."

Greisinger, A.J., Lorimor, R.J., Aday, L.A., et al (1997). *Cancer Practice, 5:147-154.*



Patient Agenda

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Provider Agenda

Understanding Potential Gaps in Treatment Discussions Between Patients With Metastatic Breast Cancer, Caregivers, and Oncologists

Musa Mayer[1]; Helen L. Coons[2]; Stephen Jones[3]; Deana Percassi[4]
[1]AdvancedBC.org, New York, NY; [2]Women's Mental Health Associates, Denver, CO; [3]Molecular Health, The Woodlands, TX; [4]Nielsen Consumer Insights (formerly Harris Interactive, Inc.), Rochester, NY

- More open dialogue is needed between patients, caregivers, and oncologists.
- Discrepancies exist between important discussion topics and actual discussions between patients, caregivers, and oncologists.
- Patients and caregivers want greater discussion about long-term treatment plans, goals, complementary or integrated Tx options, and referrals to support services.
- Patients want to understand treatment options, have active roles in decision making, and balance treatment efficacy with side effects.
- Most want information to prevent or minimize side effects: want their healthcare teams to proactively manage side effects.

Presented at the San Antonio Breast Cancer Symposium, December 9-13, 2014.

Aspects of Care Patients Value Most

- Consistent attention to quality of life, including the control of pain, nausea and other symptoms and side effects, as a concurrent goal with control/treatment of their cancer
- Encouragement to openly share symptoms and side effects, including those difficult to discuss, without fear of “bothering” the treatment team, or being seen as a “complainer”
- Routine assessment of symptoms and side effects by treatment team, preferably with a symptom checklist
- Feeling listened to regarding symptoms and side effects
- Within reason, sufficient time with oncologist and other members of the treatment team, especially for patients with many symptoms or who may have difficulty disclosing

Musa Mayer, November 7-9, 2013. Lisbon, Portugal. Advanced Breast Cancer International Consensus Conference.

As nurses, our greatest power may be to “witness”.

You Are Not Alone!

- Use multidisciplinary approach for patient and staff support
- Recruit and utilize mental health experts, experienced colleagues, spiritual counsel, patient advocates, risk management, and family.

Burklin, Y., Hunt, D.P., (May, 2018), *Southern Medical Journal*

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

-- Maya Angelou

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