

Effective Communication Across the Cancer Trajectory:

What Patients Can Teach Us

Symposium 7: Helping Health Professionals Acquire Communication Skills
GLOBAL BREAST CANCER CONFERENCE 2011
Seoul, Korea Oct 6-8, 2011



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- Importance
- Complexity
- Examples of What Patients Can Tell Us
- Examples of What We Can Learn
- Implications for Practice

Differences of System and Context



The Value of Effective Communication in Cancer Care

- Dignity through difficult transitions
- Courage in the face of daunting prospects
- Cognitive mechanisms to cope with fear
- Personalized guidance
- The feeling of being well informed



Contribution of Breast Cancer Advocacy Movement



Complexity of Creating Communication Standards and Guidelines

- Subjectivity
- Human experience
- Nuanced
- Dynamic



Particularity of Illness Context

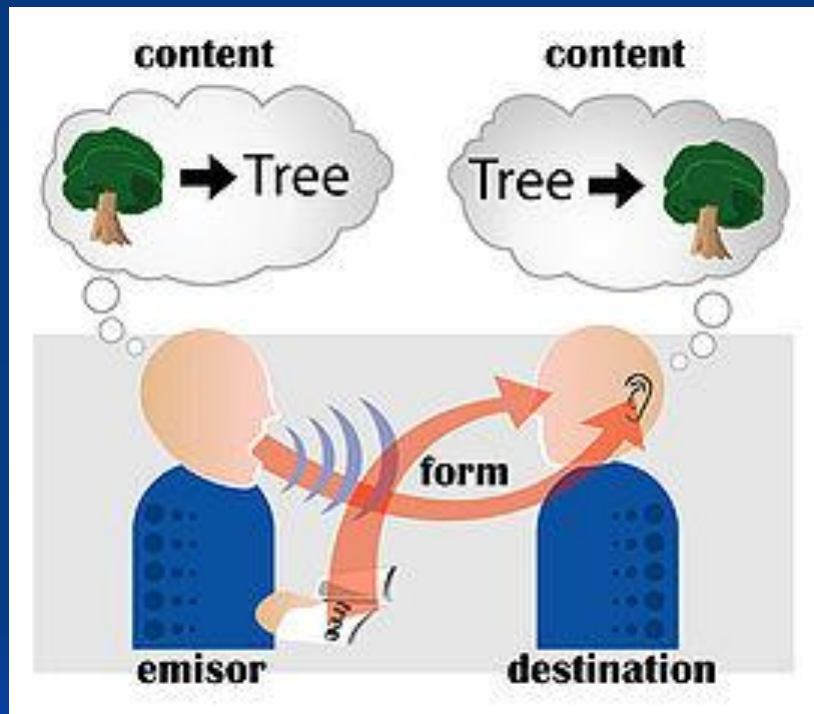


Human Diversity

- Needs and preferences
- Experiences
- Beliefs and Understandings



People are not Robots





THE UNIVERSITY OF BRITISH COLUMBIA
BRITISH COLUMBIA CANCER AGENCY



Cancer Care Communication Research Program

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Funding: NCIC (2001-05), CIHR (2005-09,
CCSRI (2009-12)



Communication Focus

Human perspective

Subjective experience

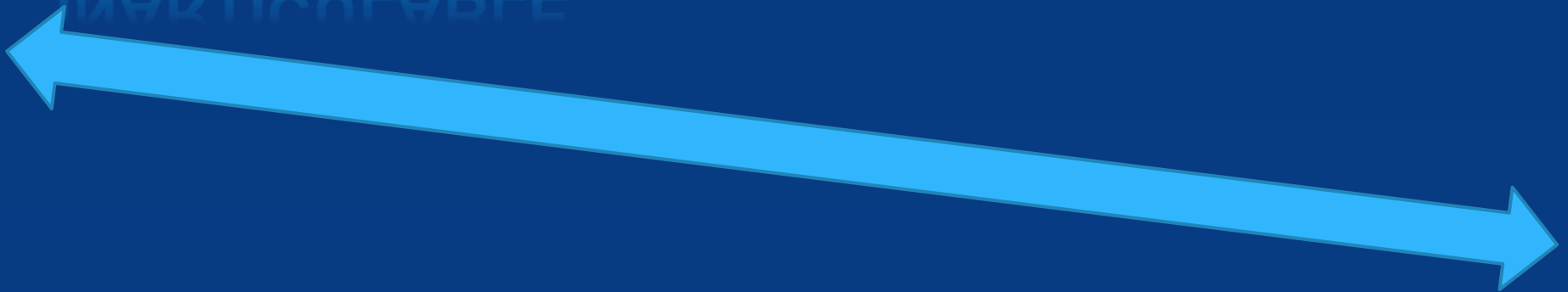
Patterns in patient self-reports



Communication as Continuum



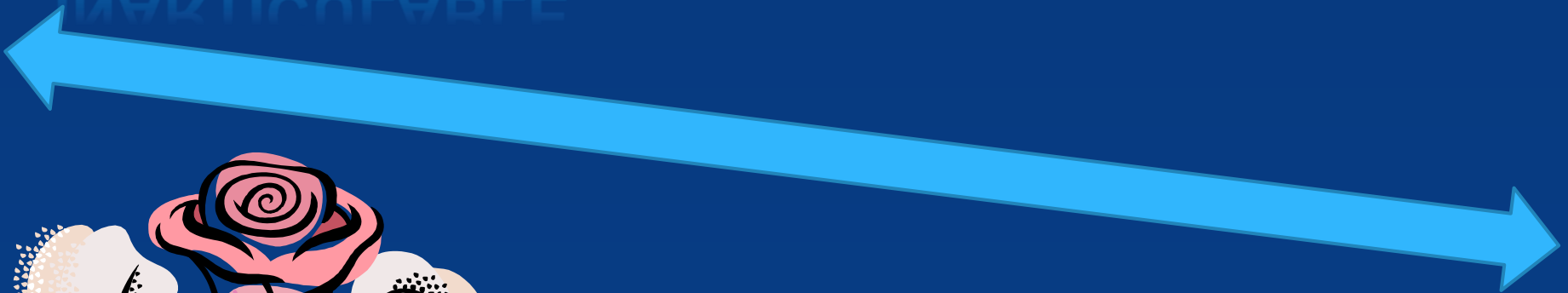
INARTICULABLE



MEASURABLE

Conventional Communication Research Approaches

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MEASURABLE



Communication Focus for Applied Research

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Clinical Care Domain

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Knowledge Sources

- Pattern recognition
- Theoretical interpretation
- Testing in practice
- Expanding on variations
- Systematically asking patients



Qualitative Contribution

- Challenge our assumptions about communication
- Consider layers of complexity to enrich our understanding
- Extract relevant practice knowledge



What Patients Tell Us



The Good News

- What we are teaching matches what patients believe is right
- Much of what we do is effective and meaningful for patients



Being Known



And then I went to the cancer clinic. Everyone was so nice and explained every step of the way and made sure you were secure and not scared. The care was like a big, beautiful family.

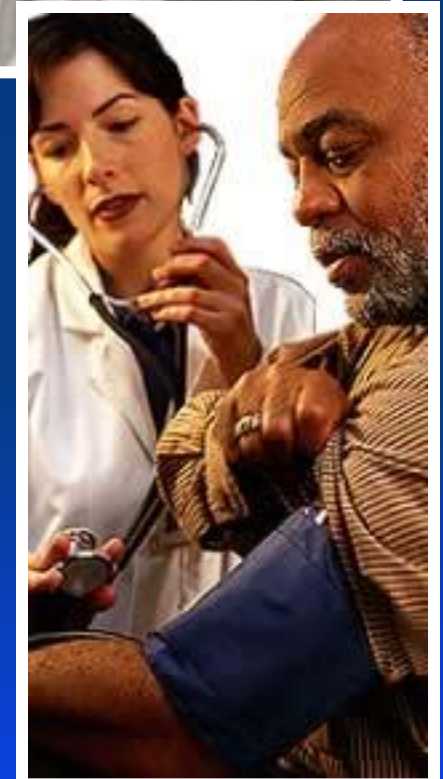
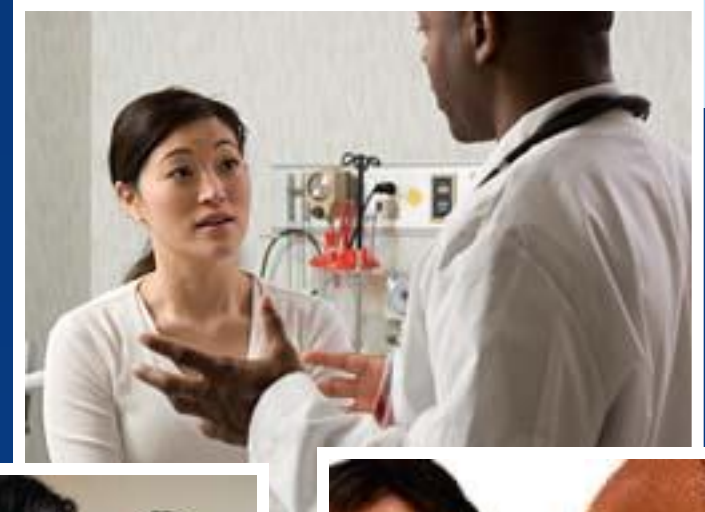
Feeling Respected

You lose your hair, you lose body parts, sometimes you lose control of body functions. You have all these indignities on a daily basis. You need somebody that doesn't treat you like some kind of sick animal. That's where the respect comes in.



Responsiveness

He has very good wording when he speaks with you. When you have something to say, he stops and he listens to what you have to say because he knows that thousands of things are running through your mind.



Sustaining Hope

He said something to me that I will never forget—word for word—at that first visit after the diagnosis. He said, “I can’t lengthen your life and I won’t shorten it. But I promise to be with you every step of the way and make it as comfortable as possible for you.” And that’s all it took from him to calm my fears.



Communication: The Power to Heal



I left there thinking, 'Yes, life is going to go on!' I made that decision there when I left that day. Up until that point I wasn't sure. She validated that, and she gave the strength to carry on.

The Bad News:

Power to Harm



- Poor communication still prevalent
- Encountered by many patients
- Creates a barrier to care
- Detracts from quality of life

The Challenge of Unintended Messages

*Lots of people
in their fight with cancer
lose their spirit.*



Truth Telling



He seemed to be very quick in his examination of my breasts, then basically gave me some ultimatums and gave me some statistics regarding death right away.

Informed Consent

They just give it to you black and white, you know, so there's no misunderstandings but it's hard that way. They should just ease, ease into it a little bit. You have to figure out how to soften the blow.



The Power of Probability



The doctor should not tell patients you have how many months to live because every individual is different, our immune systems are different. Once they've told the patient, then they start thinking about dying and then, mind over matter, they die.

The Challenges of Trajectory and Diversity



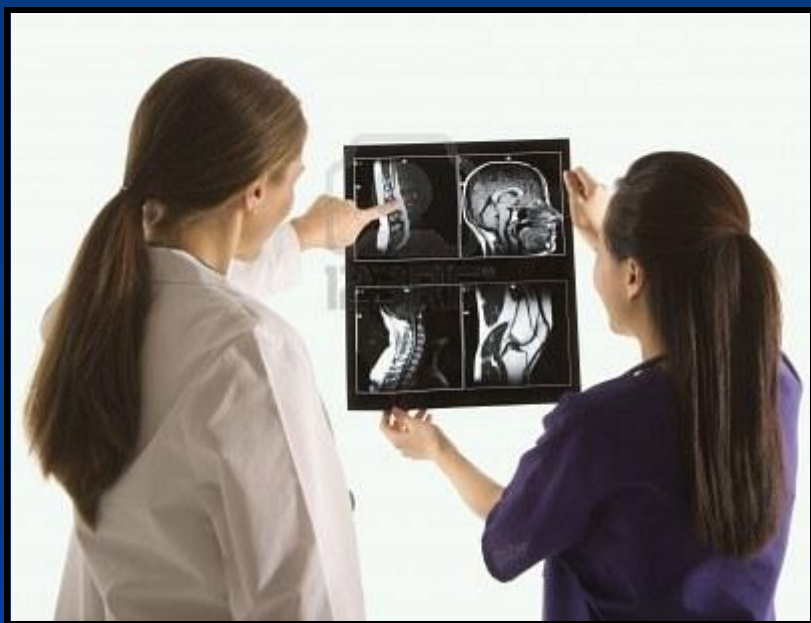
*Now, I felt very lost.
I don't know what to do to
empower myself, to protect
myself, from it coming
back.*

Partners in Care



Appointments were being made for me without my knowledge and consultation, so I don't feel that I was entirely included in the process at all...And it was really important for me to know what was going on. Because it leaves you feeling so totally out of control.

The Shared Decision-Making Agenda



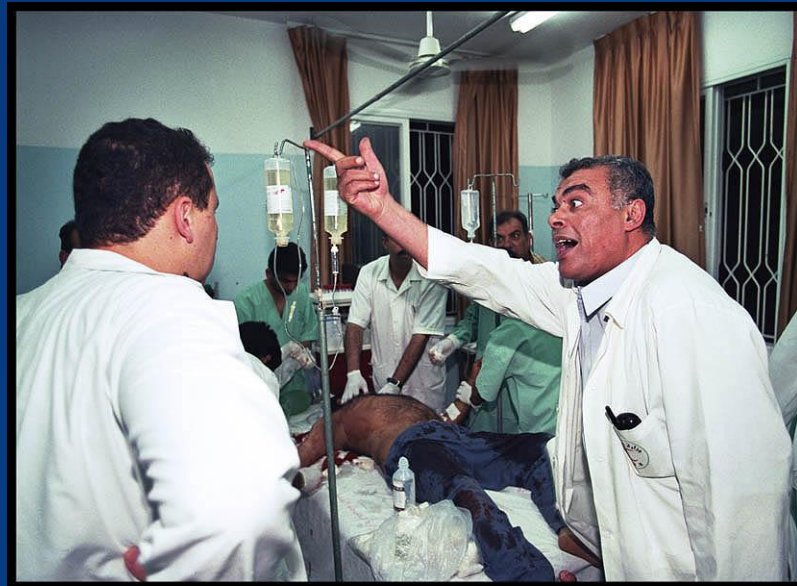
*I felt abandoned....
When she said you can
have a lumpectomy or
this or that and then
just was quiet, I
thought 'That's
outrageous!' Please.
There's a right answer
to this question!*

End of Treatment/Survivorship



They tell you everything to expect while you're on chemo in terms of your GI tract, what's going to happen to you, and stuff like that, and how the chemicals are going to affect your body in terms of hair loss and stuff like that. But once they're not actively treating you any more they're not interested anymore.

Persistent Problems



- Demeanor
- Attitude
- Emotional intelligence

Harshness



I do not want to know that in six months I won't be here. What he was basically saying to me was 'Why are we wasting our time on you?' That's what came out.

Pessimism

Now I know a doctor can't be all smiley and all up when the situation is really all down. But here you've got to have a sense that there's hope.



Destroying Hope

Surely you know that giving hope to someone is a better quality of life, even if they were dying, than hopelessness.



Nursing Roles:

Enabling System Flaws
vs Advocating for our Patients

Buffering

- Interpreter
- Connector/navigator
- Primary point of ongoing contact

Protecting

- Name it as harm and act on it

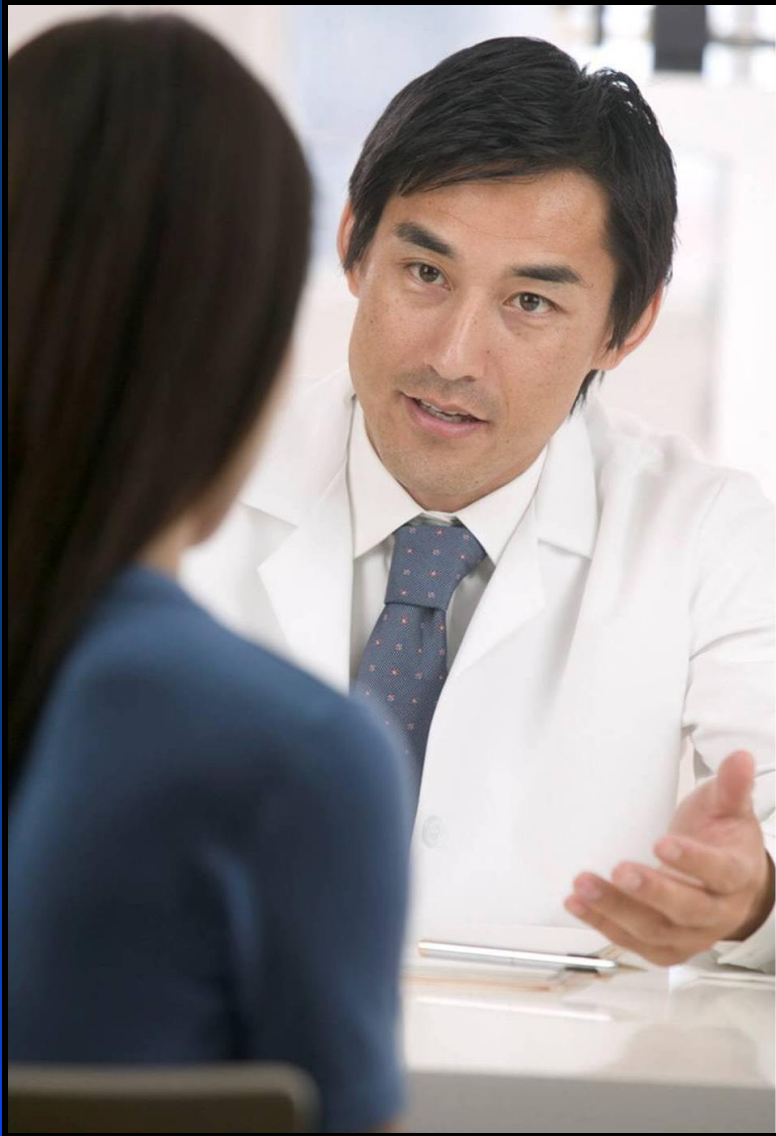
Educating/Managing

- Just as we don't give up on our patients, we should not give up on our colleagues.



Advocacy and Speaking Out





Because
communication
really matters





Excellent Cancer Care Communication:
Every Patient's Basic Right

