



A View from Two Trenches: Survivor and Researcher

Kay Bartholomew, Ed.D., MPH

October 29, 2010

Who am I?

- Researcher at the University of Texas School of Public Health
- Self-management of chronic disease
- Educational psychology and public health

Who am I?

And like many of you, a person whose life is divided by many milestones....

- ❖ Before and after the birth of my son Robert...
- ❖ Before and after my doctoral degree....
- ❖ **Before, During and After** my breast cancer

My approach to this talk

- My first public mix of my research with my personal cancer experience
- A **cranky** cancer patient
- The social aspects of the breast cancer experience?
- Question our assumptions about what cancer patients and survivors need from those around them

**Day 1 “You are a member of an elite club
.....cancer cannot change your
essence”**

- Remember ... I was a cranky cancer patient
- In general, we, the cancer and health care community enforces **the tyranny of a positive attitude**
- We impose a judgment of what is good coping

So, what is “good” coping?

- Whatever works for the woman
- Instrumental getting the job done
- Emotional expressing or not expressing feelings
- Flexible
- Socially supported

Who does a positive attitude help?

- The health care system; the support system
- NCI systematic review of research suggests that there is no one right approach to coping with cancer
- A moderately realistic attitude may be more related to good outcomes than a constantly upbeat one

Day 23 *“Here are some more books...”*

- The myth that all people need the same (i.e. A LOT of information)
- The reality ... everyone needs ENOUGH information and what is enough is individual
- Research is quite clear about variability in information seeking

Day 63 ***“Well we all know why you got this cancer ... and you got rid of him.....”***

- Our friends and family need a lot of skill-building in dealing with us in helpful ways
- Inverse of the cultural icon of the cancer fighter ----- we bring cancer on ourselves and that if we fight hard enough we can cure it

The complexities of cancer

- Friends, family, health care providers -- extreme care to not blame the victim
- Reconsider our personal war on cancer language *Lost the battle Waged a valiant fight....*
- For a woman dealing with cancer may be a job ...a dance...a garden...an exercise..... a range of metaphors

Day 150 ***“Do I have to re-arrange all of my social relations at the very same time I fight this infection?”***

- The myth that everyone has social support or a team
- Or that the social support has a firm grasp of roles and tasks --- or the skills to perform the roles and tasks
- Or that the people we expect to “show up” are the ones who do

What might help?

- Instructions
- Women can't ask for what they need most
- Social barriers to asking – for example, to help me with housework; to come during chemo but to bring a book; to be with me, but not to do anything; to not talk today

Day 264 ***“Cancer is job 1”***

- Being a sister, daughter, mother, wife, person is job 1
- Keeping a job; doing a....might be job 2 or even job 1
- Cancer is another job
- Just because a woman gets through three jobs in a day, it does not mean she doesn't need anything

Day 365 “*Where have you been?*”

- 168 discrete medical events
Procedures, tests, surgeries, ED visits,
hospitalizations, chemo administrations,
radiation treatments, doctors visits
- Where have **you** been?

Day 1825 *“Do you keep patients focused at the ends of their noses because there is some evidence that this is helpful to them?”*

- Like information seeking, patients vary in their need for planning and control

Day 1825 *“Oh, and while I have your attention..... Why don't you tell women about the permanent perky rubber chicken breast?”*