Language and Illness: A Pilot Study Exploring Conscious Language Choices Among Breast Cancer Patients

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Research Question:
How consciously did women with breast cancer make language choices when discussing their diagnosis and/or illness with family and friends?

Statement of the Problem
The American Cancer Society website estimates 1,372,910 new cases of cancer in 2005 and 570,280 cancer-related deaths. Of those new cases of cancer, 211,240 will be related to breast cancer in women. (http://www.cancer.org/docroot/STT/stt_0.asp) People diagnosed with a potentially life-threatening illness, such as breast cancer, experience increased anxiety and stress that not only can make life more miserable, but can also actually exacerbate the illness. An abundance of research connects patients’ abilities/strategies for coping with their levels of anxiety. Much of that research emphasizes the importance of communication with others as a key strategy in helping patients cope.

Contact with one’s family and friends and medical practitioners is an important activity that can help patients wrestle with their emotions in the wake of their diagnoses and progression of their illnesses.

A key challenge with the research is it does not say how that communication should happen. Specifically, the research rarely, if ever, focuses upon actual language choices patients can, or should, make in trying to describe their experiences so as to reduce their levels of stress. Instead, the research focuses on aspects of communication, such as timing or setting. Research also explores changes in patterns of communication within families, but again, that research tends to focus on timing and setting more than actual language choices and word usage.

In contrast, there has been an increase in research and training for medical practitioners, especially doctors, on conscious language choices when sharing potentially fateful diagnoses. In addition to timing and setting, practitioners are encouraged to use specific words or phrases that enable patients to process the diagnoses in safe and nonjudgmental ways. Based on a literature review, however, research on patients’ conscious use of language in an attempt to reduce stress and anxiety is virtually non-existent.

According to general semantics (Korzybski, 1958), the way people talk about their perceived realities is a process of evaluation. If those evaluations are valid, anxiety and stress can be reduced. If, however, those evaluations are incorrect, anxiety and stress increases. General semantics suggests the actual word choices and sentence structures used in those evaluations can literally affect levels of anxiety. For example, in our society, the word “cancer” would hardly be viewed as a positive word. It is a scary word that for many is equivalent to the words “death” and “suffering.” But does all cancer lead to death and suffering? No. A patient might instead describe her disease as “cancer cells located in a tiny area of my left breast.” This change in wording is not only a more correct evaluation of the disease, but it also creates room for hope of treatment and possible recovery which, in turn, could reduce current and future levels of stress and anxiety.

As the United States witnesses increased diagnoses in life-threatening illnesses, especially cancer, the need for personal coping strategies also increases. One of the principles of general semantics, is that the language patients use to think about or describe their ‘realities’ can influence levels of stress. If true, it is important to research language usage among patients with potentially life-threatening illnesses to identify strategies that positively reduce anxiety and stress.
Rationale for Choice of Problem/Situation

In terms of academic research on communication and cancer, most articles focus on timing and setting (Barnes, et al., 2000; Fox, et al., 2004). Furthermore, much of the research in this area is housed in the discipline of psychology versus the discipline of communication. As a result, pre-existing surveys used to measure communication quality do not fully measure communication aspects. Instead, surveys used tend to measure “relationship satisfaction” or “supportive interactions,” (Fox, et al., 2004; Figueiredo, Fries, and Ingram, 2003) using aspects of communication interactions as an indicator. The problem is that psychologists may not emphasize communication theory, especially in terms of linguistic choices and message formulation. As a result, survey questions don’t fully measure communication interactions and rely too heavily upon respondents’ assessment of quality communication. Definitions for terms such as “open communication” or “self-disclosure” are rarely offered which prevents respondents from accurately identifying communication behaviors and prevents researchers from accurately interpreting the data in terms of communication outcomes.

There is surprisingly little research within the communication discipline related to this issue of language choices and life-threatening illnesses. The research that does exist tends to use more traditional communication theory as a foundation for study, including uncertainty reduction theory, social identity theory, and communication accommodation theory (Sniderman, 1996). Other communication research employs communication constructs such as frequency, encouragement, honesty, emotional satisfaction, and communication satisfaction (Gotcher, 1990, 1993; Hudspeth, 1995). Interpretation of data from such research does tend to correspond more directly to communication quality than does the psychology research; however, research into actual word usage and shaping of messages is still largely overlooked.

Research rooted in general semantics is possibly the only research that explicitly looks at the effects of language choices when dealing with a potentially terminal illness. That research, however, is also extremely limited; only two articles were found after exhaustive searching across disciplines (Middleton & Lieberman, 1993; Hoffmann, 1988). Both articles fully explore general semantics linguistic aspects; however, they are both narrative in nature and are limited to personal reflections versus formal study techniques.

Dr. Isabel Caro, (2003), has performed extensive research using general semantics techniques in psychotherapy which has resulted in her development of a Linguistic Therapy of Evaluation. She has successfully merged the psychology and communication disciplines in regard to language and emotion. Caro’s research and findings fully focus on the positive impact of helping patients make conscious choices in word usage and message formulation in helping reduce levels of stress and anxiety. The success of her work points to the need to translate her efforts into other populations, including those facing potentially life-threatening illnesses.

Limited research needs to be built upon to further identify what communication strategies, especially in terms of word choices, are most beneficial to patients, their families, and their health practitioners.

Method

Participants. Six women diagnosed with breast cancer within the past three years were recruited through a local breast cancer support group and personal referrals. The mean age of participants was 55.3 years. Five of the six women were married and had children; three subjects had children younger than 18 at the time of their diagnosis. Three subjects had prior cases of breast cancer in their family histories.

Procedure. Subjects participated in a standardized open-ended interview (Patton, 1990) to describe their experiences in communicating their diagnoses and talking about their illness with family and/or friends (Appendix A). Specifically, participants were asked about language choices made during those discussions. The standardized open-ended interview format had participants answer the same questions, “thus increasing comparability of responses” (p. 289). Interviews were transcribed and sorted into “recurring regularities” categories (Guba & Lincoln, 1981, p. 56).
Results

1. Importance/satisfaction with communication. All six subjects said it was very important to be able to talk about their diagnosis and course of treatment with family and friends. Four of the married subjects reported it being especially important to be able to communicate with their husbands.

   [My husband] has been absolutely wonderful. He’s a total keeper, and I spent a lot of time expressing to him what my concerns were. [CB]

   It was important; it was important for me to hear. I mean we just jumped right into this thing and started getting educated, and that helped. [MB]

   The whole thing was pretty devastating. I called my husband right away. [PE]

   My husband, you know, he and I are our support systems. He’s there for me, I’m there for him. I can’t say enough in being able to share with somebody because anything that can help ease the burden for you to be able to concentrate on yourself and get through a day is tremendous. [JR]

   Three of the subjects reported talking with friends was not as easy as talking to spouses. Friends appeared to either be dismissive or did not want to directly talk about the issue:

   I think in our country in particular, you’re expected to shut up, put up with it, go forward, not talk about it. And I think people are afraid to bring it up, because they’re afraid you’re going to fall apart. I waited for people to ask me, though, to sort of be given permission to finally talk about it. [LS]

   One particular friend really just thought it should be quiet, but she’s the only one. [MB]

   I was offended by all their ‘you’ll be fine’ stuff, because that just piles on the worry, I think, because I know they don’t know what they’re talking about. I did say to one person, you know, it’s interesting you tell me I’m going to be okay when I haven’t even heard that from a doctor yet. I think it’s people’s inability to really know what to say or how to say it. [SH]

2. Semantic reaction to the word “cancer.” All six women reported that prior to their diagnosis, the word “cancer” evoked a strong negative response, largely related to death.

   Terminal, suffering, no hair, emaciated, the end of the road. [SH]

   Pretty much death. [MB]

   On a gut level, it scares the living crap out of me. [CB]

   You’re going to die. You know, maybe you’ve got a year, maybe you’ve got a few years. But you get cancer, and you’re going to die. [PE]

   Following treatment, however, the women reported feeling more hopeful in terms of the word “cancer,” understanding it may not necessarily lead to death. The possibility for recurrence, however, was reported as being taken into account:

   I’m much more hopeful, much more confident. But you know your throat tightens up a little bit when you go in for the mammogram and think all right, is it going to show up. [MB]
Of all cancer types, breast cancer just seems to have a higher recovery rate, so it’s not as scary to me any more. [PE]

3. **Language choices for naming and describing the diagnosis.** All six women reported purposely using the words “breast cancer” when talking with spouses, adult children, and adult friends, despite their negative knee-jerk reaction to the word prior to diagnosis. No attempt was made to use other words or metaphors.

> I don’t couch my language in, you know, terms to make things soft. I told people “I have breast cancer” and “I had radiation.” [LS]

> I called it ‘cancer’ because I found the doctors wouldn’t call it cancer. Nobody wants to say ‘cancer.’ They would call it tumors, suspicious area, a little bit of cloudiness. For me, I can’t deal with things unless I know what it is. [SH]

> We definitely used the word ‘cancer.’ There were not any punches pulled. [CB]

> I’m a strong believer in telling [my adult children]. I said ‘breast cancer,’ and I would say it was ‘invasive.’ After I told them all that, I backed it up with saying the doctor said the prognosis is good. I think I needed to hear myself say it out loud, too, so I could deal with it. [MB]

> Yeah, yeah, we called it ‘cancer.’ I think we both pretty much knew what it was and knew we needed to deal with it. [PE]

However, subjects who had children under the age of 18 at the time of their diagnosis, did report being more conscious about language choices when talking with their children.

> We talked with each of our kids individually, because they each would hear things differently. The oldest one was able to deal with more details than the other two could. We were pretty careful as far as how much information we gave our little guy, because we didn’t want to frighten him. We did say ‘breast cancer’ to him, but I think we used more general terms like ‘mommy was going to the hospital’ and ‘mommy was going to have some surgery’ without fully sidestepping the issue. [JR]

> I was concerned my 14-year-old son would think death the minute he heard . So I had a talk with him about the fact I had cancer and what was going to happen. You know, I was going to be going through these treatments, and worst case scenario, he would be seeing some bald lady puking all the time. But we didn’t talk a lot about it. [PE]

> My advice is just to never have a 16-year-old boy and cancer at the same time. At that age, they are so busy, and they are so intent on being independent, and so very self-centered. And it’s not his fault. I mean, I know he was internalizing a lot of things and it was hard for him to talk about things, but I was always honest with him. I may not have told him every last detail, but I told him what I felt he could manage at his age. And I used the word ‘cancer’ all the time. [CB]

4. **Language choices for describing the treatment process.** Five of the subjects suggested they were more purposeful in language choices when describing their reactions (physical and emotional) to medical treatments for the breast cancer than they were in sharing news of their diagnosis. Overall, subjects were concerned about sending negative messages that would promote pity or frustration in family members or friends. Efforts were made by subjects to provide positive oral accounts, regardless of actual feelings or emotions.
I always said “I'm doing fine.” My firm belief is when you're strong and give the perception to others that you’re handling it, your friends can be of greater support to you. I would rather live with than be pathetic with my cancer. Maybe I’m training them to give me more strength than I have at the time when I need it. But when you get into a pity party, what’s the good of that? Your friends will soon abandon that whole thing because they don't want to be around anybody who just draws from them all the time. [SH]

I was tired and there was pain involved. But I would say quite often I felt very lucky and very blessed that it was caught so early and the treatment was going so quickly. You need to be honest but also upbeat. Show the positive sides of things. You have to give the kids and your husband that ray of hope. [MB]

I think you have to be really careful not to give people more than what they can handle, and you know, it hurts me to say this, but sometimes you have to put them before you. I think there are people that you love so much that you don’t want to hurt them. You’d almost rather never have to tell anybody than to have to hurt them, but you know that you have to do that because you need them for support. You know what you need to have for yourself and for your comfort, but sometimes it’s better not to even share that if it’s going to hurt the person that you’re communicating with. [CB]

I think if you dwell on the negative, everyone just feels worse. It’s all so cumulative, you just didn’t want people to get tired of listening to you whine. A lot of how you talk about it depends upon how people respond to you. If you say something about cancer and you can sense the people are starting to get nervous, you just kind of shut it down. You can sense when people don’t want to talk about it, and I’m sure it’s because they’re scared. They know that if it happened to you, it could probably happen to them. [PE]

I wasn’t going to wallow in self-pity, and with my close friends, I kidded about it. Which was very helpful. It made it easier because it’s not this big dour thing that’s frightening and all that. [LS]

5. Information on making language choices when discussing the diagnosis and/or treatment. All six women reported they had been given an abundance of information related to their diagnosis and planned treatment from medical providers. However, none were able to recall information that explicitly focused on purposeful language choices when discussing their diagnosis or treatment with family and friends. All of the subjects said they likely would have read such information, but overall, they felt they were not likely to have done anything differently in terms of how they spoke with spouses and adult children. Subjects who had children under the age of 18, however, did suggest such information would have been helpful in talking with their children, especially in terms of developmental stages of children and their ability (or inability) to process information.

You get inundated with materials. I would have read such a thing and it might have helped, but I did things my own way. [PE]

There’s a lot of information about how to talk with your physician, and I think there was information about talking with your family. [CB]

I think I would have read information about talking to your kids. I think I did okay, but it would have been helpful. [JR]

I just think women probably just figure out [how to talk about the illness] on their own, because they figure everything out about running their home. They’re givers. How do you feel? Is it your stomach? It’s all of those things we do naturally. But it would have been nice to know how to talk to my son better. [SH]
[Information] would have probably been good, but I did okay with it, but I think that would be an excellent thing to do right at that first appointment. [MB]

Conclusions
The pilot study attempted to understand how consciously women with breast cancer made language choices when discussing her diagnoses/treatments with family and friends. All subjects reported it was important to be able to talk about her illness with family/friends. Communication with spouses was especially important for married subjects.

Furthermore, most of the women consciously chose to use the words “breast cancer” or “cancer” when speaking with family and friends, despite the initial negative semantic reaction they, had to the words. No attempts were made to modify or find a substitute for the word “cancer.” Many of the subjects suggested their choice to use the term “breast cancer” helped them to wrestle with the disease in a forthright way.

However, women with children under the age of 18 were more mindful of the amounts of information given to children. While most still used the words “breast cancer,” other words were sometimes substituted and/or parents avoided speaking about the disease entirely unless the child raised the subject.

When communicating about their experiences with treatment procedures, most of the women reported feeling compelled to be more conscious in their language choices by using words and phrases that painted a positive picture and protected the feelings of family members and friends. Language that was hopeful and/or minimizing of symptoms was used to prevent hurting the feelings of others or to maintain relationships.

Limitations
Limitations to these findings include the fact that the number of subjects was quite limited. Also, subjects were all Caucasian, were well educated, and were economically stable. Generalizing may be limited to this demographic, as well as this form of cancer. Lastly, subjects’ observations and recollections were not corroborated with family and friends’ experiences.

Implications for further research
Most of the women reported having positive communication experiences with family and friends. One could wonder if that relates to the increased level of awareness about breast cancer in our society over the past 8 to 10 years. To that end, would subjects with other forms of cancer have similar positive communication experiences with family members and friends?

Gender implications related to the communication experiences might also be further explored. The fact that all subjects were women likely plays a role in their comfort with and/or desire for communication. Gender aspects might also be further explored in regard to the subjects’ concern for protecting the feelings of others when reporting their experiences with treatment. How might these feelings relate to women’s roles as “nurturers” and “mothers?” Would male patients feel as compelled to protect the feelings of others when sharing their experiences?

Finally, research into purposeful language choices when speaking with children about breast cancer diagnosis and treatment in developmentally appropriate ways could be a support to breast cancer patients. Subjects who were parents at the time of diagnosis suggested such information would have been appreciated.

General semantics training should also be considered for breast cancer patients to help minimize stress and increase hope. For example, the principle of “dating” could help patients cope with the possibility of remission. Patients can remind themselves that every case of cancer is unique, so the initial experience with breast cancer does not equal a later experience. Another example relates to the general semantics idea “the map is not the territory.” Subjects reported purposeful use of the words “breast cancer” to describe their illness does not paint a complete picture, as every woman’s experience with breast cancer is unique. Both diagnoses and experiences with treatment are different among patients, so to use the global moniker of “breast cancer” could be misleading in terms of anticipated disease...
progression. Finally, general semantics principles could help with anxiety about the future. Describing the future requires one to "project," which is hardly a reliable endeavor. The best patients can do is gather information and make converging inferences to prepare them to cope with whatever does happen.

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References


Appendix

Interview questions:

• How long ago were you diagnosed with breast cancer?

• Can you help me understand your health situation today in light of your past diagnosis of breast cancer?

• When you were first diagnosed with breast cancer, how important was it for you to talk about that diagnosis with your family and friends?

• After sharing the initial news of your diagnosis with family/friends, how important was it for you to continue to be able to discuss your diagnosis and illness with your family/friends?

• Prior to your diagnosis, what images or feelings did the word “cancer” evoke in you?

• Does the word “cancer” still evoke those same images/feelings today? If not, what has changed? Why do you think the change occurred?

• How easy or difficult was it for you to talk about your diagnosis/illness with family/friends? What specifically made it easy/difficult?

• How carefully did you choose your words in those discussions? How conscious were you about your or others’ language choices in those discussions?

• What were some of the words you used to describe your diagnosis?

• What were some of the words you used to describe yourself (thoughts/feelings) during treatment(s) and recovery?

• Were there any words you purposefully used when discussing your diagnosis or illness with family/friends?

• Were there any words you purposefully avoided using when discussing your diagnosis or illness with family/friends?

• Do you recall receiving any information or materials that offered advice about ways to talk about your diagnosis/illness with family? If so, do you recall if those materials stressed actual word choices?

• What advice would you give to a breast cancer patient in terms of discussing her diagnosis/illness with family and friends?