



Breast Cancer Survivorship: The Role of the Primary Care Physician

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September 12, 2007

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Research Seminar



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Background

- Breast cancer is the most commonly diagnosed type of cancer in women.
- It is estimated that in 2007, there will be 178,480 new cases of breast cancer diagnosed and nearly 40,500 women will die this year.^{1,2}
- According to recently published research³, there was a stabilization in breast cancer incidence rates during 2001-2003, ending increases that started in the 1980s.
- Mortality rates decreased between 1990 and 2002 2.3% annually.⁴

¹Breast cancer can occur in both men and women, but male breast cancer is rare. It is estimated that in 2007, 2,030 men will be diagnosed with breast cancer (1.1% of total) and 450 (1.1%) will die from it.

²<http://www.cancer.gov/cancertopics/types/breast>

³Howe, HL et al. Annual Report to the Nation on the Status of Cancer, 1975-2003. Cancer 2006;107:1711-1742.

⁴Breast Cancer Facts & Figures, 2005-2006, American Cancer Society.



From Cancer Patient to Cancer Survivor: Lost in Transition

- Breast cancer survivors represent 22% (2.3 million) of the survivor population, which is around 10.1 million.⁵
- These higher survival rates are attributed to earlier detection and improvements in breast cancer treatment.
- Breast cancer survival, however, can bring with it physical and psychosocial effects which may occur years after treatment ends.

⁵Institute of Medicine. 2005. *From Cancer Patient to Cancer Survivor: Lost in Transition*. The National Academies Press: Washington, DC.



From Cancer Patient to Cancer Survivor: Lost in Transition

- The IOM (2005) defines a late effect as “unrecognized toxicities that are absent or sub-clinical at the end of therapy and become manifest late with the unmasking of hitherto unseen injury because of any of the following factors: developmental processes, the failure of compensatory mechanisms with the passage of time, or organ senescence.”



Late treatment effects for breast cancer survivors*

- Cancer recurrence
- Second primary cancer
- Arm lymphedema
- Premature menopause
- Estrogen deprivation
- Weight gain
- Cardiovascular disease
- Fatigue
- Cognitive impairment
- Psychosocial distress

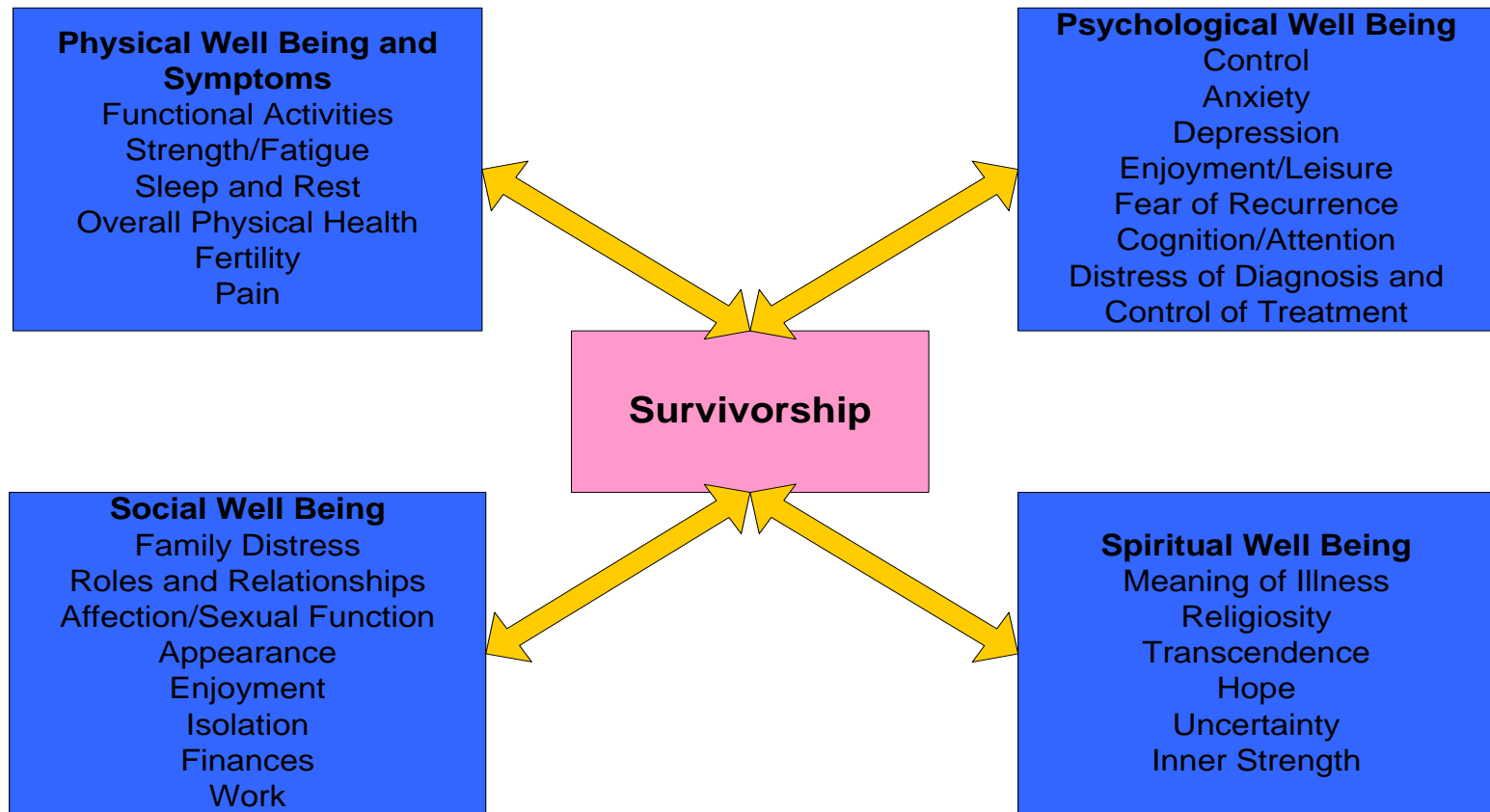
*See handout for more details on each late effect.



From Cancer Patient to Cancer Survivor: Lost in Transition

- Cancer survivors of all types remain understudied and misunderstood by research and health services delivery communities.
- “Although some cancer survivors recover with a renewed sense of life and purpose, what has often not been recognized is the toll taken by both cancer and its treatment – on health, functioning, sense of security, and well-being. Long-lasting effects of treatment may be apparent shortly after completion or arise years later. Personal relationships change and adaptations to routines and work may be needed. Importantly, the survivor’s health care is forever altered.”

Quality of Life Model⁶



⁶City of Hope Beckman Research Institute (2004).



This pilot study

- Exploratory qualitative research project conducted to:
 - Gather data on how breast cancer survivors are provided information regarding the late effects of their cancer treatment;
 - Understand how breast cancer survivors' health is followed by both cancer specialists (e.g., radiation, surgical oncologist), cancer caregivers (e.g., social workers, dieticians), and the survivor's primary care physician; and
 - Generate ideas about how their post-cancer experiences could have been improved either by their health care providers, or by the survivors themselves.



Study subjects and recruitment

- Interviews with:
 - 10 breast cancer survivors who had completed treatment by March 30, 2006; recruited through breast cancer survivor group; flyer at lymphedema clinic at Ellis Fischel
 - 7 oncologists; recruited through UMC/Ellis Fischel
 - 8 primary care physicians; recruited through FCM
- One focus group (n=9) with nurses (RN and APN), social workers, and physical therapists specializing in cancer care – recruited through email sent to potential participants, names provided by colleague at Ellis Fischel.



Methods and Analysis

- All interviews and the focus group were taped.
- All tapes were transcribed verbatim by a professional transcriptionist.
- Transcripts were analyzed using an editing organizing style⁷ most closely associated with grounded theory.

⁷Miller WL, Crabtree BF. 1999. Clinical research: a multimethod typology and qualitative roadmap. In: Crabtree BF, Miller WL, editors. Doing qualitative research. Thousand Oaks, CA: Sage Publications; p. 3-30.



This presentation

Framed around where and how primary care physicians can have an impact on the quality of care that a breast cancer patient receives before and during her treatment and ultimately, the quality of care a survivor can receive post-treatment.



Broad topics

- Providing patients with information about treatment options
- Knowledge concerning late treatment effects
- Having adequate support during and after treatment
- Care triangles/shared care model – creating and maintaining



Providing patients with information about treatment options

- Making patients aware of treatment options

"I think the biggest part of my discussion in that time period and part of my talking with them is trying to give them some ability to make some decisions and give them the ability to start taking control of their life again" (oncologist).

- Patients are often unaware that options exist, which often creates an immediate dilemma – what to do?
- Patients want guidance, in many cases



Need for guidance

“They give you the information, but the decision is up to you and you have to weigh out all of the stuff that they are telling you and of course it’s way over your head, but you try to make the best decision. What I wanted to know from a doctor was, ‘What would you do if it was you or your wife?’ He said, ‘Don’t even go there.’ He gave me the sign with his fingers crossed. He would not even answer that. I did not care for that too much. I thought, ‘I want to know what you would do if it was your wife or mother or whatever.’ It would have helped me to know that, but he didn’t think that was appropriate I guess” (survivor).



Need for guidance

"I had no idea what to expect. I wish that there had been somebody to kind of walk me through the procedures, somebody, maybe a mentor or something. Somebody the office could have had, 'Okay we have these five women who've been through this. Maybe they can help you work through it.' I think there is a lot of support afterwards for people with the support groups and breast cancer support groups. I know that when my friend was diagnosed, she called me to talk. She knew from a mutual friend that I had cancer. I called the mother of one of my son's friends who had been diagnosed six months before I was (survivor)."



Need for guidance

“After your treatment is over, then you kind of think, ‘Did I do the right thing or not?’ And here I’m in a breast cancer support group and so many of those women have had chemotherapy, I didn’t have to have chemotherapy. I always worry, ‘Should I have had it?’ I had to actually talk with a social worker about that and she helped me through that. She let me know that none of the doctors there would have let me make that decision if it wasn’t right. They would have been begging and pleading with me if I needed that and chose not to have it (survivor).”



The late treatment effects

- Survivors generally did not feel they were given much information, but “information” is a double-edged sword.
- Oncologists felt that you should give them enough to make informed decisions:

“They don’t want to hear it. You tell them but it doesn’t sink in. It’s not that they don’t understand it because they hear ‘cancer,’ and that is the end of it, for that day anyway and maybe for that week. In my opinion, you need to give them an overall survival bit of information and probably the benefit of each therapy. I don’t think you need to go over all of the other non-lethal toxicities that impact survival. I mean, you need to do that I suppose, but not at that first visit. It is already more than they are going to be able to absorb” (oncologist).



The late treatment effects

- But treatment can alter them in subtle, but none the less, frustrating ways ~

“I did know my body would change after the chemo and the radiation and everything, but what you’re not really prepared for is the fact that you go from being a vibrant woman into I guess your crone stage, you know, affectionately” (survivor).



The late treatment effects

“I don’t think people are prepared and the healthcare profession isn’t prepared to deal with it. I didn’t lose hair but there is a big difference in what happened to my hair. My hair is now white. It wasn’t white, it was very streaky gray, but it wasn’t white. Now I color it all the way through. My skin is incredibly dry and I expected that to happen in the breast area and under my arm, but I can’t control it. My eyes, I got bifocals after the surgery, but since then, my eyes have gotten so bad. I sent my son to an ophthalmologist and I talked to her about it after my surgery and she said, ‘It happens with radiation. They don’t tell you. Your body gets better but your eyes never do.’ I went to the dentist. I go every six months and they told me to use calcium replacement wash and suggested that I have my teeth whitened. So I did and the insurance refused to pay for it because it’s cosmetic. This was not something I would have done before the cancer, but it’s cosmetic. They wouldn’t pay for anything. These are all little things, but I was very in tune to that, all of these little things” (survivor).



The late treatment effects

- What they do hear –
 - Lymphedema, but they did not feel that information was made clear

"I just think that somewhere along the way somebody needs to let them know that, soon after their surgery or during radiation or whatever. Usually there is information there at these different sites, there are little booklets on lymphedema, but how do you know if it relates to you if you don't pick it up and read it?" (survivor)

- Recurrence and development of second primary cancers



The late treatment effects

“I’m not sure anybody realizes that you keep your diagnosis forever. You are never done. It just continues. You are faced with your mortality every time you look in the mirror. Everybody has problems. Somebody else has kidney disease. Somebody else has heart problems, but I think the person doesn’t expect that, ‘Okay, I’m not just going to get a pill and get better I’m going to have this forever.’ Your whole family then has that. Every time you go to the doctor, ‘Is it okay? Are you all right? Is this the day?’” (survivor).

“To put it bluntly, I want to make sure I am right with the Lord. If I’m going to leave this world early, I want to know that I’m in the right place” (survivor).



Having adequate support during and after treatment

- Receiving the diagnosis

“The person that called me wasn’t the radiologist. My internist was notified and he asked to be the one to call me. He knew me over the long term, so he called me at work and delivered the news that it was breast cancer there. He was very kind to me. He was very, very concerned about this outcome for me” (survivor).



Having adequate support during and after treatment

- Being “released”

“Oh I was depressed. I mean, that is a very common thing, because as you go through treatment, you see your doctor at least once every three weeks, usually once a week for months at a time. You feel like somebody is taking care of me now.” It’s very common for people who finish treatment to be very depressed and I was” (survivor).

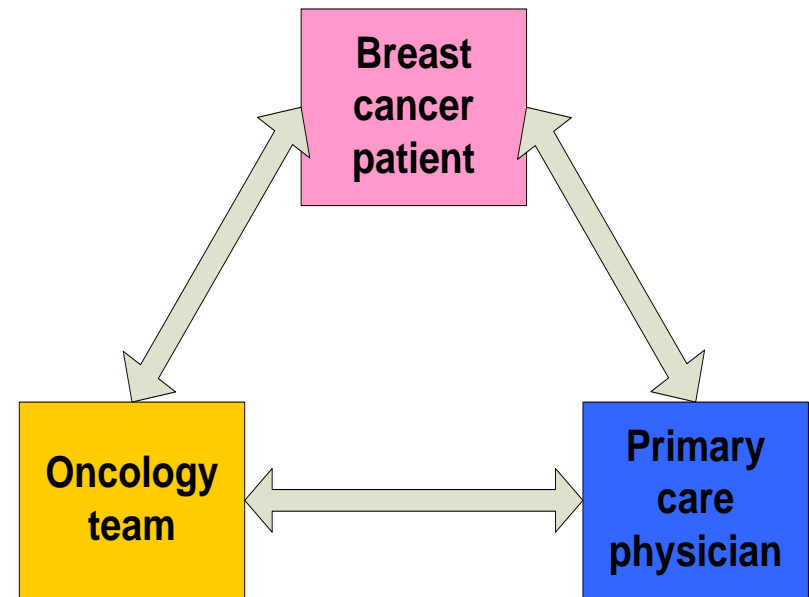


Having adequate support during and after treatment

‘I just remember in the days when people were in the hospital most of that time and then it would be a discharge day when they were done and the day before would be the big, ‘Oh, you’re going home. You’re done. It’s going to be great.’ Then they get a fever that night. You know, they didn’t want to go home. They were too scared or nervous or whatever. They would have physical symptoms the day before a discharge even when they were doing great. I think that is some indication that there is fear there” (FG).

Creation and maintenance of the care triangle – shared care model

- Assumes communication and relations between the patient, oncology team, and primary care physician.⁸
- It is dependent on the specialist and PCP having a clear understanding of what is involved in the care and what the roles are.



⁸Nielsen, JD et al. Randomised controlled trial of a shared care programme for newly referred cancer patients: Bridging the gap between general practice and hospital. *Qual Saf Health Care* 12(4):263-272.



Creation and maintenance of the care triangle – shared care model

- PCP typologies – one oncologist’s viewpoint
 - PCPs that do not have a comfort level with managing care during or after – rare
 - PCPs who treat oncologist as a consultant and want to manage care entirely – rare
 - PCPs who desire *co-management* of care during and after treatment – most common



Creation and maintenance of the care triangle – shared care model

“Hopefully they [oncologists] can have confidence that I’m going to take care of all the other stuff so they don’t have to worry about that. If I pick up something that I think is cancer related, I will send that person back quickly to them. I’d like for them not to have to think about any other medical problems besides what they are seeing them for and that is true of any other specialist I interact with. I would hope that they think that they don’t have to worry about that because I’m doing a good job on all those other things. I think the patient has confidence in that as well” (PCP).



Creation and maintenance of the care triangle – shared care model

- Easier said than done
 - Roles are not made explicit when treatment is done.
 - PCPs' knowledge of late treatment effects:

"Some new things that come out, I don't feel like hit my radar or are in the literature that I look at. Things change so rapidly from the different kind of protocols and things. I would find it very beneficial to have an annual review of the comments, the top ten common treatments and what is the long term effect and what do I need to do about that. There may be some review literature that I just haven't looked at" (PCP).



Creation and maintenance of the care triangle – shared care model

- Current culture of co-management or lack thereof:

“Our culture is one of not making it [co-management] an emphasis for interns and residents and students and not doing it very well ourselves, and so we create poor communication based on our culture. It is a self-fulfilling culture in perpetuity” (oncologist).



Creation and maintenance of the care triangle – shared care model

- Some lack of communication between PCPs and oncologists
 - “One way street of communication” – a system related issue
 - Oncologists feel they don’t get information regarding cancer related problems when patients are hospitalized or are seen by other physicians
 - PCPs indicated that they are not notified when shared patients are admitted either



Creation and maintenance of the care triangle – shared care model

- Lack of communication between patients and PCPs
 - Don't see PCP during treatment
 - Tired of going to doctors when treatment ends
 - Did not have a regular PCP before diagnosis – don't see the point of getting one



Creation and maintenance of the care triangle – shared care model

- Strong bond created between patient / survivor and oncology team:

"At one time, I would have given him [surgical oncologist] every health problem I had because he had helped me through some difficult things. I could have brought everything to him, my risk of high blood pressure, diabetes, arthritis. If I could have brought anything, I would have let him manage it because I trusted him so much" (survivor).

"If my oncologist sent me back to a primary care doctor, that would feel like my mom sending me off to live with an aunt."



Creation and maintenance of the care triangle – shared care model

“For better or for worse, we’re locked into a very intense relationship with our patients. This is life and death stuff. Most of the time, we see patients when they are going through the worst experience of their lives or one of the worst experiences they’ve ever had. That makes people fearful. At the same time, it brings out the best and most wonderful qualities in human beings as well. It is really important to me to see somebody I treated 10 years ago who is in remission and is sending me Christmas cards and I’m hearing about their family. That is very sustaining. It is sustaining in what can otherwise be a very morbid, emotionally draining specialty” (oncologist).



Creation and maintenance of the care triangle – shared care model

- Need for change in the current model? Numbers of oncologists to treat cancer patients:

"You could look at this and say it's a self-serving debate on the part of oncologists who are trying to offload themselves and their responsibilities. If the projections are correct⁹, and they are frightening actually, there is going to be a big shortage of oncologists given the shape and curve of cancer in the aging population. So it's on the basis of those kinds of predictions that people say, 'Look, something has got to happen.' The oncology practice will have to change radically. So I think for better or for worse, what will happen is increasing emphasis on some of the things that oncologists do now are being taken care of or being taken over by primary care physicians. We'll probably have to learn new ways to better communicate about that (oncologist).

⁹Erikson, C et al *Future supply and demand for oncologists*. www.jopasco.org, March, 2007.



Reminder....

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Communicate and support patients at all points in the process

"Generally, I try to set up a follow-up visit for patients. I like them to come back and let me gather the information after their oncology visit and sit down and talk about what they understand is going on so that I can help clarify the medical terms and things like that so that they have a clear understanding, not only of the diagnosis, but also the potential treatments. A lot of people, it's interesting, have a lot of questions about things and they want to come in and talk to me before they start treatment. They want to bounce those ideas off somebody else. I appreciate being kept in the loop (PCP)."



Communicate and support patients at all points in the process

"The nice thing about the EMR is if I see something isn't going well or just sounds like they are having a hard time, I see that in their notes. I will just give them a call and so that is just another nice way to have them feel like there are more people around" (PCP).



Communicate and support patients at all points in the process

"Many times I may see just that patient in the family, but sometimes I see three generations and so it's helpful for me to know if somebody is not doing well. I see the whole family so then I'm not blind-sided if they say, 'Oh you didn't know that so-and-so was in the hospital. They took a turn for the worse.' Or somebody had a relapse and was hospitalized for something I would like to come and visit them as a social visit just to say hello" (PCP).



Communicate and support patients at all points in the process

- Post-treatment may be when they can hear about the late effects of their treatment:

"I don't remember them [information about late effects] very specifically. Now I think I need to go back and read some more about the long-term effects to reeducate myself. I think I heard it. I might have somewhat absorbed it. I know what radiation can do...involvement of the heart and things like that. They did go over it. I couldn't give a lecture on it right now, but it is something I do need to go back to" (survivor).

- Speak to them about the late effects that move beyond the physical – the psychological, social, and spiritual.



Inform patients by being informed about what they need

- Make sure that patients are scheduling and getting to follow-up visits with oncologists
- PCPs need clear guidelines of the roles of all the players
 - Oncologists need to communicate with the PCPs about what they want and need PCPs to do
 - This should also be communicated to the survivors as well

Inform patients by being informed



“It would be nice after the treatment is all over that they [oncologist] send you a kind of a summary thing and say, ‘Now I would like to see the patient twice a year and I will be getting their mammograms.’ And I usually ask the patient, ‘Who’s getting the mammograms and when are they done?’ It would be kind of nice to have it laid out and I don’t feel that my toes are stepped on if they say, ‘I want to see this patient twice a year and I’ll do their mammogram.’ That’s fine. I just want to make sure somebody is doing it” (PCP).

Cultural shift – moving toward the shared-care model



- Leave the Laggards¹⁰ behind...

"Some of it is a technical solution, but most of it is just to give up on the people that won't do it and start from scratch, teaching students and residents and rewarding people that do it. Not with fancy cash prizes, but by holding them up as exemplars of that pattern of behavior. There is no good, easily identifiable way to do that. Because it is not something you necessarily get service quality hero recognition for, being a good communicator over months to years with both patients and family" (oncologist).

- Make the connections with patients

¹⁰Rodgers model for the adoption and diffusion of innovations



Getting the PCP involved

- Oncology team needs to insist that a PCP be involved – can be a natural connection

"I had felt the strongest connection to my being a breast cancer survivor among my medical oncologist, my nurse oncologist, my surgical oncologist and interestingly enough my gynecologist. It was in his office that the mammogram was done that the diagnosis came from. I see that gynecologist annually. I always feel that connection. He has concerns and weighed my lifestyle, genetic risk factors for ovarian, cervical, and breast cancer. We always had a conversation about that. I don't know if that would have come up if I had seen someone who wasn't with me during the breast cancer diagnosis. I really feel that there are people being vigilant on my behalf" (survivor).



Conclusions – Essentials of Survivorship Care¹¹

- Prevention – recurrent, new cancers, or other late effects
- Surveillance of the above cancers and assessments of the late effects
- Intervention for the consequences of cancer and its treatment
- Coordination between specialists and the PCPs to ensure that adequate care is given

¹¹Institute of Medicine. 2005. *From Cancer Patient to Cancer Survivor: Lost in Transition*. The National Academies Press: Washington, DC.



Questions

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