

# Surviving vs. Thriving after Breast Cancer: Bridging the Communication Gaps Between Survivors, Cancer Specialists, and Primary Care Providers

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# Collaborators and support

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# Objectives

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- Discuss problem areas regarding communication and information sharing identified by breast cancer survivors, cancer specialists, cancer caregivers, and primary care providers during post-treatment breast cancer care;
- Introduce a thrivership model of care outlining roles and responsibilities of post-treatment breast cancer survivors, cancer specialists, cancer caregivers, and primary care providers and;
- Present examples of materials to be used to facilitate the implementation of a thrivership model of care.



# Today's presentation

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- Results from two exploratory qualitative research projects
- Qualitative research
  - Takes place in “natural” settings
  - It is emergent
  - Fundamentally interpretive
  - Holistic view
  - Examples of methods: interviews, focus groups, participant observation, document analysis



# *From Cancer Patient to Cancer Survivor: Lost in Transition<sup>2</sup>*

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- Breast cancer survivors represent 22% (2.3 million) of the survivor population, which is around 10.1 million.
- 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 – late treatment effects.

<sup>2</sup>Institute 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*

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- 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.”



# The Late Effects of Breast Cancer Treatment: A Study of Breast Cancer Survivors, Cancer Specialists, Cancer Caregivers, and Primary Care Physicians

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- 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.



# The Management of Late Treatment Effects in Breast Cancer Survivors in Rural Areas: An Exploratory Study<sup>1</sup>

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- Assess rural primary care providers' awareness, understanding and knowledge of breast cancer late treatment effects.
- Assess rural breast cancer survivors' awareness, understanding and knowledge of breast cancer late treatment effects, and to assess their health information needs regarding breast cancer survival.
- Develop and pilot test patient-specific breast cancer treatment care summaries for both survivors and primary care physicians, detailing the treatment and potential implications for late treatment effects on subsequent health problems.

<sup>1</sup>The project was sponsored by a grant from the Mid-Missouri Affiliate of the Susan G. Komen for the Cure Foundation.



# Study subjects

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- Individual interviews with:
  - 25 breast cancer survivors
  - 7 oncologists
  - 11 primary care physicians
- One focus group (n=9) with nurses (RN and APN), social workers, and physical therapists specializing in cancer care



# Data collection analysis

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- All interviews and focus groups were tape-recorded
- Transcribed verbatim by a professional transcriptionist
- Transcriptions read by research teams
- Themes emerged based on responses of the participants



# Findings: Issues identified by and for survivors

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- Knowledge about late treatment effects
- Management of late treatment effects
- Mental health concerns
- Confusion concerning post-treatment care
- Time spent in specialist's office
- Travel to appointments – rural survivors



# Knowledge about late treatment effects

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- Survivors generally did not feel they were given much information, or did not remember the information
  - Information is a double-edged sword – elicits additional fear
  - **(Oncologist)** “You tell them, but it doesn’t sink in. It’s not that they don’t understand it. 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.”



# What they do hear

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- Development of second primary cancers
- Recurrence
- Lymphedema, although this is not always clear
  - **(Survivor)** “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?”

# Management of late treatment effects



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**(Survivor)** “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. 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...I went to the dentist. I go every six months and they suggested that I have my teeth whitened. So I did and the insurance refused to pay for it because it’s cosmetic. These are all little things, but I was very in tune to that, all of these little things.”



# Mental health concerns

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- Were not prepared for the depression / anxiety post-treatment
- Differing reasons for depression / anxiety
  - Fear of recurrence
  - **(Survivor)** “I worry about it coming back, on occasion I do. And when you are first coming off of treatment, you want to know exactly what to do so this doesn’t happen again. But it’s like trying to grab smoke; there is no way to make sure. They can’t tell you how to not have a recurrence.”



# Mental health concerns

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- Concern that the wrong treatment choices were made
- **(Survivor)** “After your treatment is over, then you kind of think, ‘Did I do the right thing or not?’ I’m in a support group and so many of those women have had chemotherapy, I didn’t have to have chemotherapy. I worry, ‘Should I have had it?’ I had to actually talk with a counselor about that and she helped me through that. She let me know that none of the doctors 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.”



# Mental health concerns

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- Waning emotional support
- **(Survivor)** "After my treatment was over I did hit a low spot, because that was Thanksgiving, Christmas is nice and loving and all that kind of crap. Well, in January after my treatment, I became very concerned, I felt alone. I broke down once in January and just cried and made my husband just hold me. He said, 'What in the world is the matter with you? Everything is alright and you know it's alright now.' And I said, 'Shut up and just hold me.' He tried to get away and I smacked him a good one and I said, 'Hold me.'"



# Mental health concerns

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- Being “released” / connection to oncologists
- **(Survivor)** “At one time, I would have given him [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.”



# Mental health concerns

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**(FG participant)** “I just remember in the days when people were in the hospital most of that time...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.”

# Confusion concerning post-treatment care



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**(PCP)** "Sometimes patients will ask me stuff like, 'Well I'm not sure whether I'm supposed to go back to them or not.' Usually it says in their note if I have it for the patient to come back in one year. Patients say all sorts of stuff that we say or don't say. Either they hear it differently or we don't say things that we think that we said, so sometimes it's not clear to patients what we want them to do. Or it's not clear to patients what the oncology people ask them to do."



# Findings: Issues identified by primary care providers

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- Level of knowledge about post-treatment care
- Co-management is difficult – system problem
- Barriers to Patient / PCP post-treatment communications
- Lack of clear recommendations and role definition



# Level of knowledge about post-treatment care

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**(PCP)** “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...There may be some review literature that I just haven’t looked at.”



# Co-management is difficult – system problem

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**(PCP)** “Another oncologist and I are both frustrated by patients that we have getting admitted to the hospital or seeing somebody else for a key event, not for something that is like ongoing care of hypertension or diabetes, and not really putting it to anybody’s attention. It’s a terrible problem in an institution.”



# Barriers to Patient / PCP post-treatment communications

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- **(Survivor)** “You know I really don’t have any relationship with her and never have had with any doctor. I’m much closer to my medical oncologist than I have been to any other physician. I’m not even sure I will go back to her when I go back to a regular physician.”



# Lack of clear recommendations and role definition

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**(PCP)** "So one thing is clarity about who's responsible for what. I don't think the letters that the cancer doctor sends are helpful at all for me to say what to do especially after five years. They do something different in the first year, the second year, and the third year depending on what kind of cancer it is. So does the oncology staff think that by me getting the oncologist's records that then I would be able to translate that into what I'm supposed to do? No, I think that's not okay."



# Findings: Issues identified by oncologists

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- Primary care physicians' knowledge level about post-treatment care
- Co-management is difficult – system problem
- Barriers to Patient / PCP post-treatment communications
- Bond between the patient and specialist



# Barriers to Patient / PCP post-treatment communications

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**(Oncologist)** “For high risk primary cancers, they’re going to spend the better part of a year suffering through toxicities of treatment and completing treatment and the best use of their time is probably to generally not do a lot with their primary care provider during that time unless they really need it. If they have bad diabetes or bad hypertension, congestive heart failure, whatever. So then when they are done the default, I think has been for many of the patients, unless they are geriatric patients or live far away, to keep seeing their oncologist just regularly. I’m not saying it’s the better way or the worst way but it is at least in our experiences been the way.”



# Bond between the patient and specialist

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**(Oncologist)** “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. 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. That is very sustaining in what can otherwise be a very morbid, emotionally draining specialty.”



# Shifting the focus from Surviving to Thriving

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- “Finality”
  - **(Survivor)** “I don’t mind saying that I’ve had cancer. I don’t even mind saying I have it, because I think it is something that is more than just the disease. It’s something that encompasses your whole being afterwards. Some of it is that if I survive this cancer and I’m a cancer survivor, what happens if I get it again? Am I no longer a survivor?”



# Shifting the focus from Surviving to Thriving

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- “Exclusivity”
  - **(Survivor)** “People who have had breast cancer and are in remission can be called a survivor, but people who are undergoing treatment for whatever stage they might be and it’s just a continuous thing and they have no cure, they are called warriors. I really like that because that is what it is. I am in a battle for my life and I’m not just surviving. I don’t think I am going to survive. I think that this breast cancer is going to be the thing that is going to kill me eventually.”



# Shifting the focus from Surviving to Thriving

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- **(Oncologist)** “I have people who are not going to be cured of their disease that are not just surviving, but *thriving*. *Cancer thrivership* is different than cancer survivorship. I think our true aim needs to be cancer thrivership, which means a better enriched life that has some detriments because of the cancer experience, but has some added value, lessons learned, water under the bridge or whatever, that can actually be different and better. It will never be the same. It will either be worse or better and either way, it’s going to be different than what life was like before.”



# Defining “Thrivership”

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- Moves toward a life that acknowledges the cancer experience.
- The negative impact of the cancer and its treatment is surmounted.
- The survivor appropriately acknowledges and addresses their physical, social, psychological and spiritual needs post-treatment.<sup>3, 4</sup>
- Survivors are active participants in their post-treatment care.

<sup>3</sup>Weiner D, Burhansstipanov L, Krebs LU, Restivo T. From Survivorship to Thrivership: Native Peoples Weaving a Healthy Life from Cancer. *The Journal of Cancer Education* 2005; 20(3):28-32.

<sup>4</sup>Quality of Life Model, City of Hope Beckman Research Institute, 2004.



# Defining “Thrivership”

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- Survivors and providers possess adequate amounts of knowledge concerning their respective roles and responsibilities related to post-treatment care.
- There is effective communication between survivors and providers, both oncologists and primary care.
- Thrivership care includes not only the prevention / detection of new or recurrent cancers, and surveillance of cancer spread, but also interventions for problems brought on by the late treatment effects, as well as the coordination of care among oncologists, primary care providers, *and* survivors.

# Surviving vs. Thriving - Survivors



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## **SURVIVING**

- Lacks knowledge about late treatment effects
- Unsure about what clinical issues to discuss
- Assumes post-treatment care is provided by oncologist
- Rarely speaks to PCP about post-treatment care
- Either does not keep medical records and / or assumes they are kept by providers

## **THRIVING**

- Understands late treatment effects
- Asks questions about on-going health care with providers
- Providers' roles are defined
- Discusses post-treatment issues with providers
- Keeps pertinent health information



# Surviving vs. Thriving - PCP

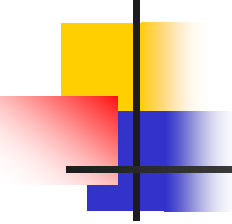
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## **SURVIVING**

- Assumes post-treatment care is monitored; post-treatment issues not often discussed
- No clear guidelines
- Unsure of what patient has been told
- Limited communication with oncologist
- Quickly sends patients back to oncologist

## **THRIVING**

- PCP involvement during and after
- Clear role definition
- Discusses concerns related to cancer treatment – emotional health
- Informs patient of who is providing particular care
- Sends pertinent tests results to oncologist
- Knows at what point patient should be sent to oncologist for additional tests



# Surviving vs. Thriving – oncology team

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## SURVIVING

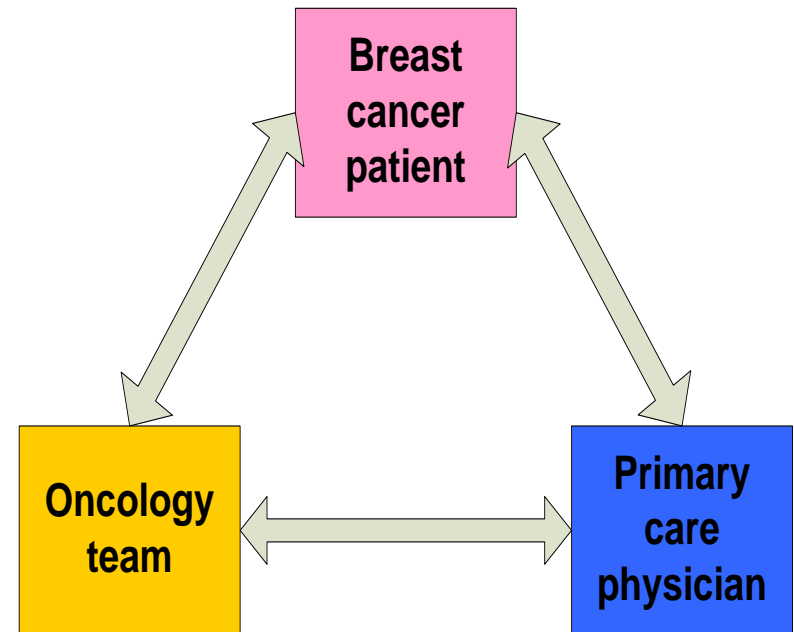
- “Follow-up care” = surveillance
- Who is PCP?
- Communication with PCP during and after treatment may not occur
- No clear guidelines defined for PCP

## THRIVING

- Provides patient information about post-treatment health, acknowledging the physical, social, psychological, and spiritual health of the survivor
- Clear guidelines and recommendations defined
- Communication with PCP
- Encourages patient to see PCP for general health care, which includes discussions about post-treatment cancer

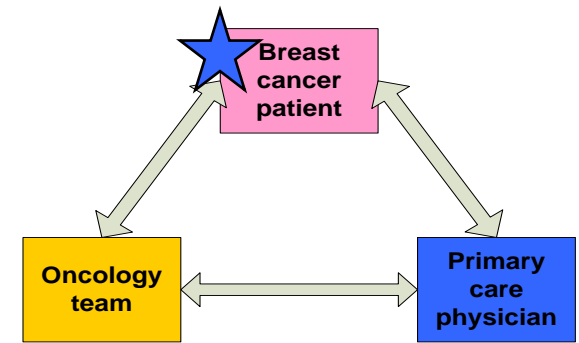
# Shared care model<sup>5</sup>

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



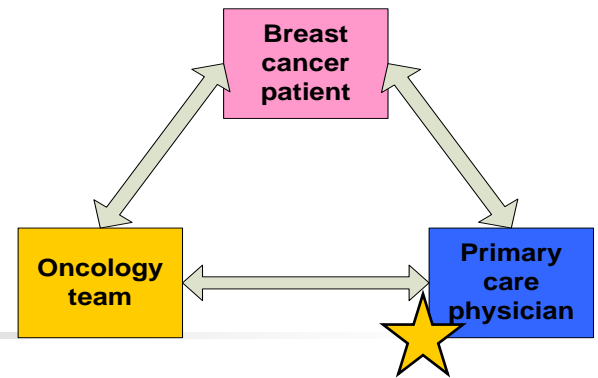
<sup>5</sup>Nielsen, JD et al. Randomised controlled trial of a shared care programme for newly referred cancer patients: Bridging the gap between general practice and hospital. *Qual Saf Health Care* 12(4):263-272.

# Shared care model



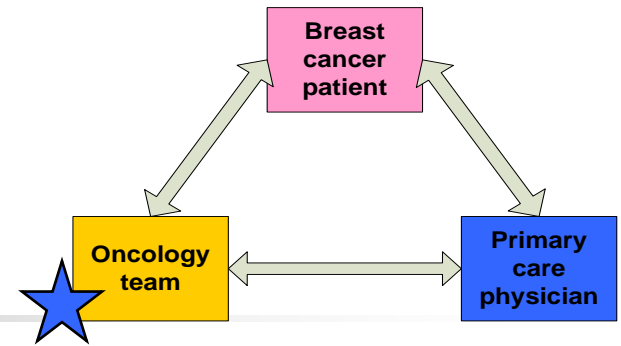
**(Survivor)** "I feel like primary care physicians should be the one that are responsible for your health and I find that lacking. They should coordinate the health care that you receive. You have a surgeon; you have your oncologist. I have a gynecologist oncologist and somebody has got to sit down and make a plan with all this information that's coming in on this patient. Somebody needs to be in charge of that. I know my specialist had sent information to my doctor, but in turn he doesn't communicate that with me. That is unsettling. You want to make sure they are receiving the correct information and all that, all those notes from your visits and any kind of lab results... who is taking care of that?"

# Shared care model



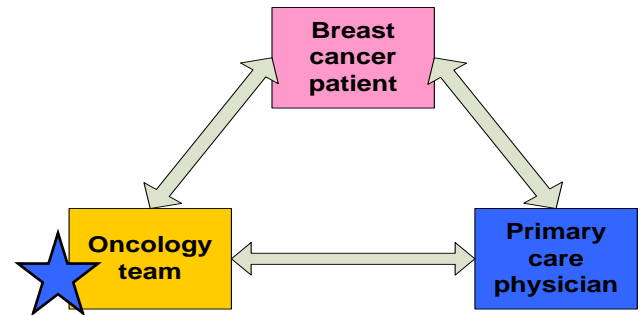
**(PCP)** "It's a partnership. It is shared care of the patient. Let her know that there are other people out there who still care and are available to deal with all of the other issues that develop. I follow directions and if the oncology folks were to send me a note saying, 'We want you to check this patient at these times with these tests. Call us if this,' I would be happy to share that with the patient, with the oncologist, so again a triad, patient, specialist, generalist, would all work together to make sure that she gets the follow-up that she needs."

# Shared care model



**(FG)** "What I hear about too is that when patients are discharged, during this intense period of time, it may be six months to two years, they are calling the provider for everything. Now they have to decide, 'When do I call my oncologist and when do I call my PCP? I don't really trust my PCP because I have this cold and I have this cough, but maybe it's going on two days longer and maybe it's the cancer back.' And then you have a PCP who knows just a little bit and the patient can't say, 'I have had A, B, and C chemo,' and what that means. There is this huge disconnect for that patient and I think for the providers also."

# Shared care model



**(Oncologist)** “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 correct<sup>6</sup>, there is going to be a big shortage of oncologists given the shape and curve of cancer in the aging population. 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.”

<sup>6</sup>Erikson, C et al *Future supply and demand for oncologists*. [www.jopasco.org](http://www.jopasco.org), March, 2007.



# Work in progress (suggestions welcomed)

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- Communication tool for providers
- Thrivership guide for patients



# Care Summary of Breast Cancer Patient for Primary Care Provider

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Patient name: \_\_\_\_\_ DOB: \_\_\_\_\_

Diagnosis:

Prognosis:

Treatment(s) received(ing):

Chemotherapy

Physician and phone number:

\_\_\_\_\_

Length of treatment: \_\_\_\_\_

Date completed: \_\_\_\_\_

Other therapy:



# Care Summary for Breast Cancer Patient Prototype – Hem/Onc

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Based on the treatment received, the following problems could develop:

- Cancer recurrence
- Second primary cancer
- Psychosocial distress
- Arm lymphedema
- Symptoms of estrogen deprivation
- Weight gain
- Cardiovascular disease
- Fatigue
- Cognitive impairment
- Premature menopause and related infertility and
- Congestive heart failure
- Osteoporosis



# Care Summary for Breast Cancer Patient Prototype – Hem/Onc

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- Follow-up plan for medical oncologist:
- For this patient, genetic counseling will be encouraged due to the type of cancer, strong family history.
- I will see this patient every 3 months for one year, every 6 months the second year, and yearly thereafter if no signs of recurrence
- During those office visits, I will:
  - Conduct a history and physical exam with focus on signs of recurrence
  - Conduct mammograms twice a year on affected breast for \_\_\_\_ years, annually on non-affected breast for \_\_\_\_ years, then annually on both breasts thereafter
  - Counsel patients about recurrence symptoms (i.e., new lumps, bone, chest, or abdominal pain, dyspnea, persistent headaches, lymphedema symptoms)
  - Encourage monthly breast self-exam



# Care Summary for Breast Cancer Patient Prototype – Hem/Onc

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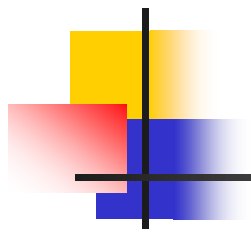
- Follow-up recommendations for primary care physician:
  - Give standard flu vaccinations yearly, pneumonia vaccine for those at high risk
  - Please forward to my office, or place in PowerChart results from:
    - Patient's yearly Well Woman exam
    - Heart-related tests
  - Please ensure that patient is making and keeping appointments with oncologist
  - Please monitor the mental health of patient. The following test may be useful to determine these factors:
    - Geriatric Depression Scale – short form
    - Beck Depression Inventory – short form
  - Encourage regular cancer screening – provide referrals if necessary
  - Conduct a DEXA bone densitometry baseline assessment at menopause; regular screens every \_\_\_\_\_ years, or every \_\_\_\_\_ if high risk
  - Work up any post-menopausal bleeding due to use of anti-estrogen agents
  - This patient (did/did not) have ER/PR positive cancer. Estrogen and progesterone:
    - SHOULD NOT be used regardless
    - May be used cautiously, with informed consent



# Thrivership Guide

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- Contains patient-specific information
- General information about Thriving
  - Maintenance of health records
  - “Validation” section
  - Reliable resources – Websites, books, magazines, local resources
  - Resources from the Komen Foundation specifically related to post-treatment issues



*Questions???*