Optimizing communication and cancer care in primary care: A physician and patient perspective.

ELISABETH KUPER MD

Learning Objectives

- Identify communication terms to utilize or avoid when discussing cancer diagnosis, treatment and long term care.
- Implement a more comprehensive and integrative approach to long term cancer care
- Formulate approaches to improve cancer care in their specific systems

Financial disclosures

- None

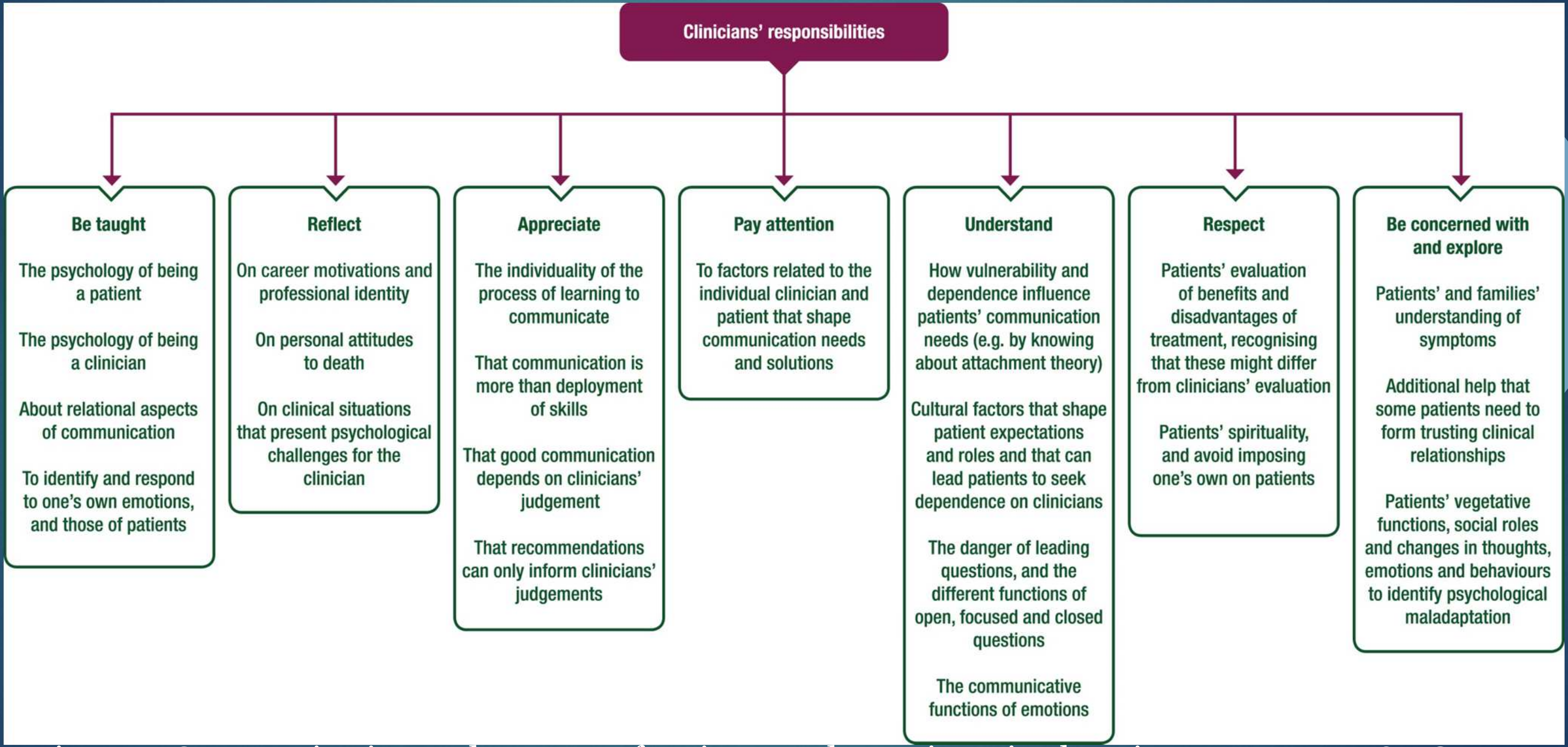
Why is cancer care in primary care important?

- More than 18 million cancer survivors in the United States in 2022 [1,2]
- Number of cancer survivors is expected to increase to 26 million by 2040[3,4]
  - Don’t forget this includes large number of survivors of childhood cancers living longer
- Varying definitions of “survivor”[4]
  - National Cancer Institute: persons from time of cancer diagnosis until the end of life
  - American Society of Clinical Oncology: Cancer survivorship care begins “in the period following acute diagnosis and treatment”
  - IOM report and others: Longer term survivors, those in post-treatment period, and persons with cancer who have survived beyond 5 years
- 2005 Institute of Medicine report called for improved awareness, definition and quality of cancer survivorship care [5]

Communication in Cancer Care

- Good patient centered communication can lead to improved outcomes [6]
  - Patient and provider satisfaction, Increased quality of life
  - Reduced patient anxiety and improved symptom control
- Context dependent
- Quality of communication relies on clinician judgement in using communication skills (per ESMO Clinical Practice Guideline 2024) [7]
  - Ability to imagine patients' feelings and needs
  - Capacity to "stay with" the suffering patient without defending themselves against their own painful emotions
  - Spontaneity, creativity and motivation
  - Biography, professional competence and experience
  - Both patients and clinicians value authenticity

Ensuring good judgement in clinical communication: clinicians' responsibilities.



Clinicians' responsibilities

Be taught

The psychology of being a patient

The psychology of being a clinician

About relational aspects of communication

To identify and respond to one's own emotions, and those of patients

Reflect

On career motivations and professional identity

On personal attitudes to death

On clinical situations that present psychological challenges for the clinician

Appreciate

The individuality of the process of learning to communicate

That communication is more than deployment of skills

That good communication depends on clinicians' judgement

That recommendations can only inform clinicians' judgements

Pay attention

To factors related to the individual clinician and patient that shape communication needs and solutions

Understand

How vulnerability and dependence influence patients' communication needs (e.g. by knowing about attachment theory)

Cultural factors that shape patient expectations and roles and that can lead patients to seek dependence on clinicians

The danger of leading questions, and the different functions of open, focused and closed questions

The communicative functions of emotions

Respect

Patients' evaluation of benefits and disadvantages of treatment, recognising that these might differ from clinicians' evaluation

Patients' spirituality, and avoid imposing one's own on patients

Be concerned with and explore

Patients' and families' understanding of symptoms

Additional help that some patients need to form trusting clinical relationships

Patients' vegetative functions, social roles and changes in thoughts, emotions and behaviours to identify psychological maladaptation

Figure 1. Communication and support of patients and caregivers in chronic cancer care: ESMO Clinical Practice Guideline☆ Stiefel, F. et al. ESMO Open, Volume 9, Issue 7, 103496

My Context

- 38 yo F with history of hypothyroid presenting in summer 2020 with worsening left hip pain.
- Fam Hx: multiple myeloma in father and maternal grandfather
- Left hip XR negative
- Felt to be likely labral tear, so MRI ordered

My context

- Left hip arthrogram showed diffuse bony osteoblastic mets
- Further work up initiated
  - CT chest/abd/pelvis and bone scan
  - abdominal MRI
  - liver biopsy
  - diagnostic mammogram and ultrasound confirmed
- ER/PR +, Her2 - breast cancer with 1 liver met and diffuse bony mets

Treatment course so far

- No local treatment (aka no breast surgery or breast radiation)
- Hormonal blockade with Aromatase Inhibitor and GnRH Agonist/BSO
- CDK 4/6 Inhibitor, ribociclib
- Bilateral hip radiation
  - Complicated by osteonecrosis of left femoral head with collapse
  - Left hip replacement
- No progression for 2.5 years, then….
- Oral chemotherapy capecitabine with no progression for 9 months
- Oral chemotherapy with PIK3CA Inhibitor, capivasertib, without effect
- Severe nerve impingement in sacrum leading to cauda equina symptoms
- Spine radiation and initiation of infusion chemotherapy, Sacituzumab govitecan-hziy, which is ongoing

Communication needs are different for each stage [9]

- Diagnosis/Early Stage
  - Bad news
  - Emotional support
  - Help to choose right treatment

- End of treatment/recovery
  - More emotional support

- Advanced Stage
  - Balance authenticity with hope

- Throughout all stages give information regarding diet, exercise and weight

Instagram: @carolynvento

Communication changes I have made

- Have a general idea of next steps, but don't expect yourself to know all possible treatments
    - Many new treatments depend on specific genetics of the tumor

- Be careful using statistics
    - Statistics can be helpful, but you are already talking to someone on the losing end of statistics

- CARES Act and open notes

Communication changes I have made

- Acknowledge the pain and difficulty of the situation
  - Waiting for work-up and treatment decisions can be one of the most difficult times
  - Immediately following treatment can be difficult
- Suppress the urge to "fix it"
  - Use language that focuses on resilience and perseverance
- Become comfortable with awkward and silence

Communication changes I have made

- Remind patients to go back to basics
  - Eating, sleeping, exercise, hydration
- Remind them that it is okay
  - To say no to people and obligations
  - To accept and ask for help
  - To not be okay
  - To still enjoy life
- Encourage them to acknowledge and accept their wide range of emotions

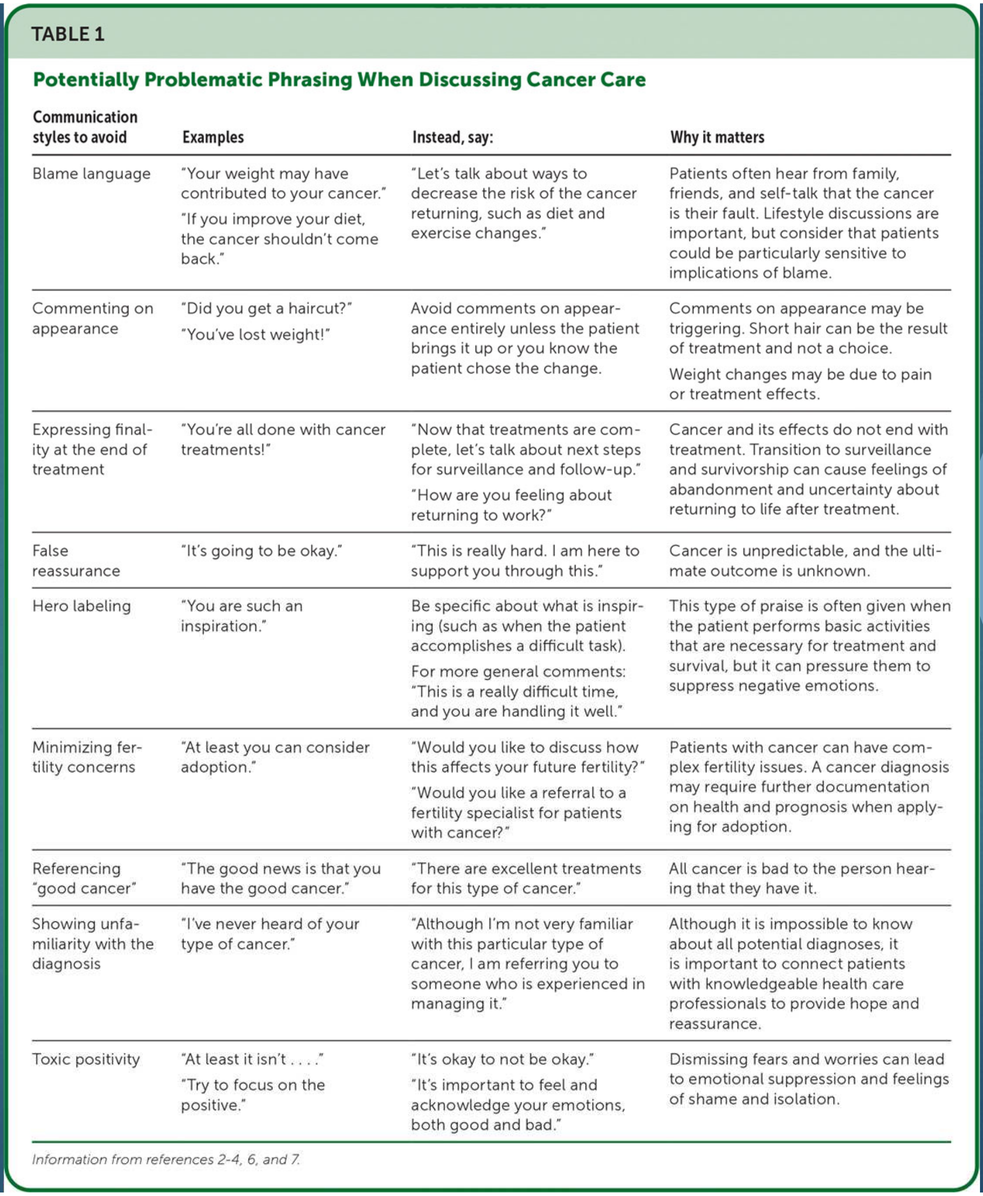


TABLE 1

Potentially Problematic Phrasing When Discussing Cancer Care

Communication styles to avoid	Examples	Instead, say:	Why it matters
Blame language	"Your weight may have contributed to your cancer." "If you improve your diet, the cancer shouldn't come back."	"Let's talk about ways to decrease the risk of the cancer returning, such as diet and exercise changes."	Patients often hear from family, friends, and self-talk that the cancer is their fault. Lifestyle discussions are important, but consider that patients could be particularly sensitive to implications of blame.
Commenting on appearance	"Did you get a haircut?" "You've lost weight!"	Avoid comments on appearance entirely unless the patient brings it up or you know the patient chose the change.	Comments on appearance may be triggering. Short hair can be the result of treatment and not a choice. Weight changes may be due to pain or treatment effects.
Expressing finality at the end of treatment	"You're all done with cancer treatments!"	"Now that treatments are complete, let's talk about next steps for surveillance and follow-up." "How are you feeling about returning to work?"	Cancer and its effects do not end with treatment. Transition to surveillance and survivorship can cause feelings of abandonment and uncertainty about returning to life after treatment.
False reassurance	"It's going to be okay."	"This is really hard. I am here to support you through this."	Cancer is unpredictable, and the ultimate outcome is unknown.
Hero labeling	"You are such an inspiration."	Be specific about what is inspiring (such as when the patient accomplishes a difficult task). For more general comments: "This is a really difficult time, and you are handling it well."	This type of praise is often given when the patient performs basic activities that are necessary for treatment and survival, but it can pressure them to suppress negative emotions.
Minimizing fertility concerns	"At least you can consider adoption."	"Would you like to discuss how this affects your future fertility?" "Would you like a referral to a fertility specialist for patients with cancer?"	Patients with cancer can have complex fertility issues. A cancer diagnosis may require further documentation on health and prognosis when applying for adoption.
Referencing "good cancer"	"The good news is that you have the good cancer."	"There are excellent treatments for this type of cancer."	All cancer is bad to the person hearing that they have it.
Showing unfamiliarity with the diagnosis	"I've never heard of your type of cancer."	"Although I'm not very familiar with this particular type of cancer, I am referring you to someone who is experienced in managing it."	Although it is impossible to know about all potential diagnoses, it is important to connect patients with knowledgeable health care professionals to provide hope and reassurance.
Toxic positivity	"At least it isn't . . . ." "Try to focus on the positive."	"It's okay to not be okay." "It's important to feel and acknowledge your emotions, both good and bad."	Dismissing fears and worries can lead to emotional suppression and feelings of shame and isolation.

Information from references 2-4, 6, and 7.

Kuper E. Improving Communication and Support in Cancer Care. Am Fam Physician. 2023 Jul;108(1):17-19. PMID: 37440730.

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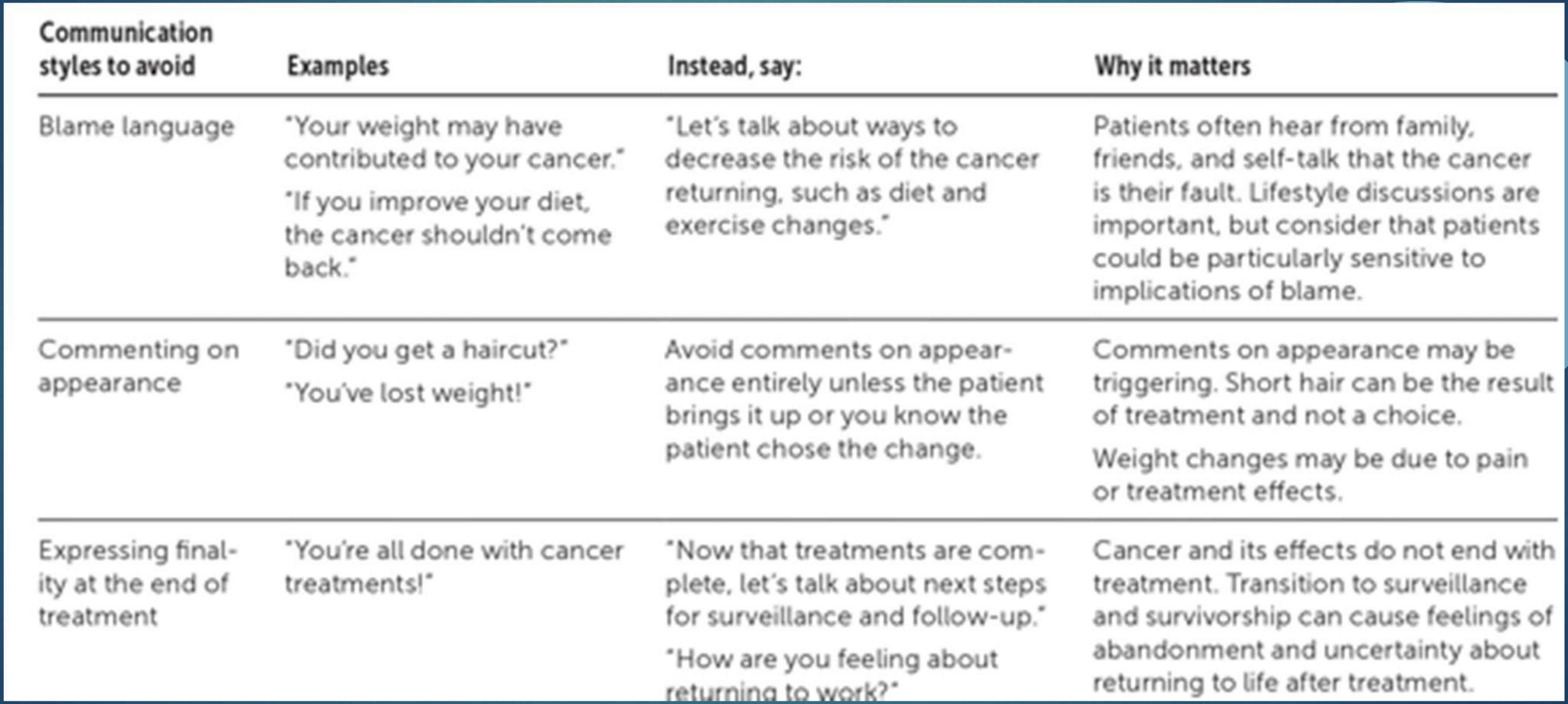

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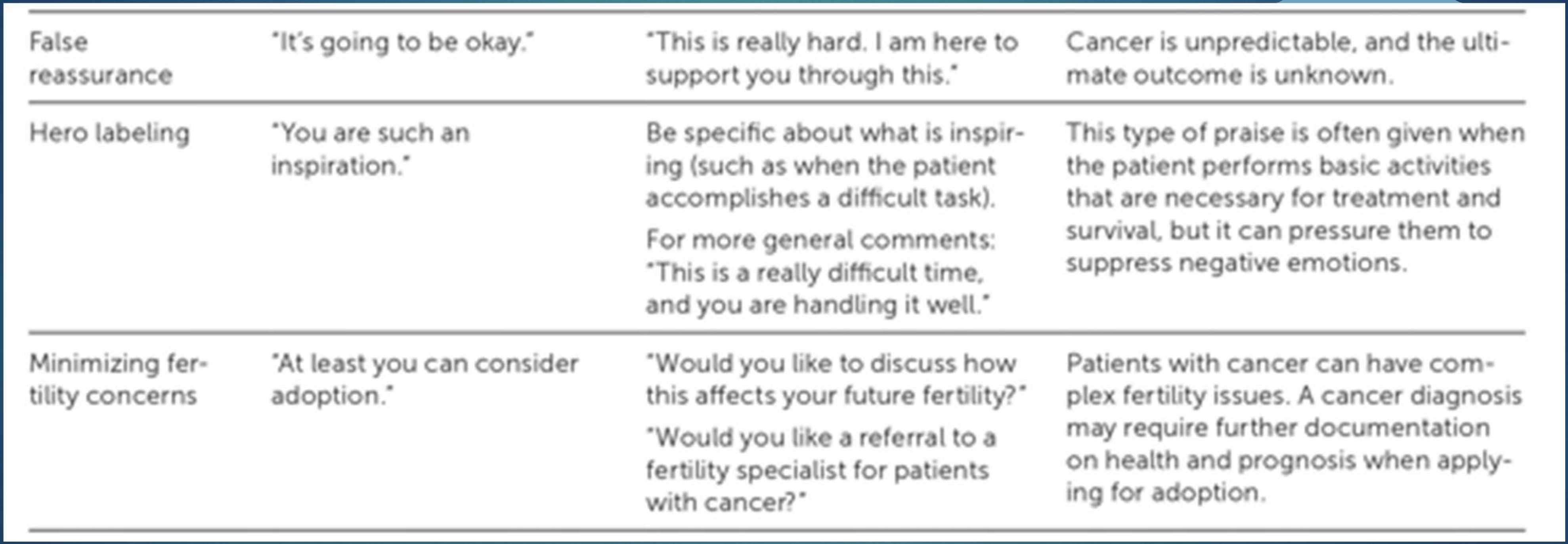

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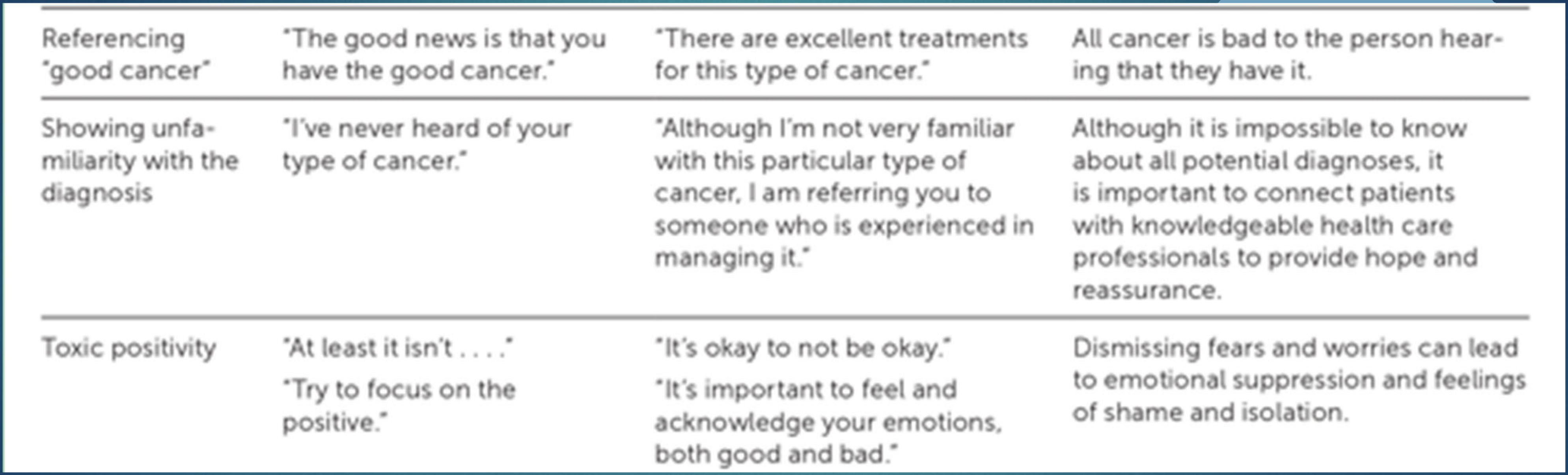

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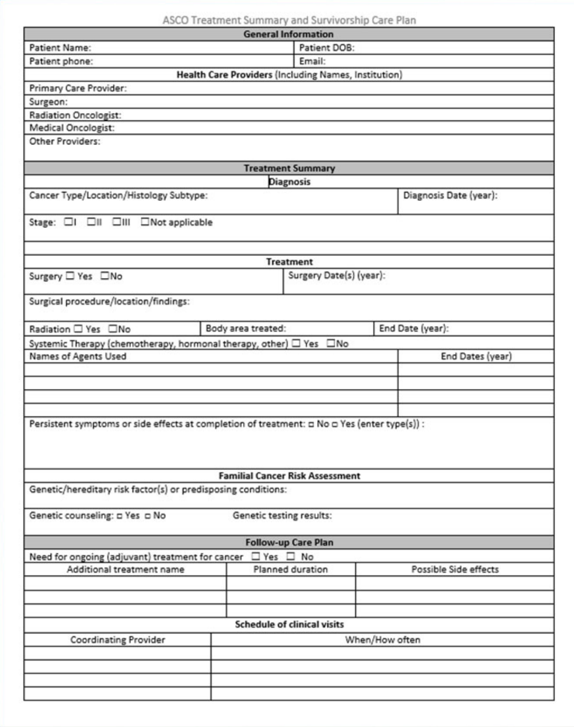
Current state of survivorship care

- Despite the seminal IOM report, there is still little standardization or systemic approach to survivorship care
- Impending shortage of oncology services to care for cancer survivors[4]
- Multiple approaches being studied[10]
  - Specialist led follow up (traditional)
  - PCP led follow up
  - Shared care between oncology providers and PCP
  - Oncology nurse-led survivorship care
  - Long term follow up clinics
  - Supported self management

Survivorship Care Plan

- Most common current approach, but not universal
  - Delivered to less than half of cancer survivors [11]
- Increases knowledge regarding surveillance and lifestyle interventions [9,12]
- No difference in distress or QOL [9, 12]
- In the few studies that looked at it, no difference in recurrence rate [9]



ASCO Treatment Summary and Survivorship Care Plan

General Information

Patient Name:
Patient DOB:
Patient phone:
Email:

Health Care Providers (Including Names, Institution)

Primary Care Provider:
Surgeon:
Radiation Oncologist:
Medical Oncologist:
Other Providers:

Treatment Summary

Diagnosis

Cancer Type/Location/Histology Subtype:
Diagnosis Date (year):
Stage: ☐I ☐II ☐III ☐Not applicable

Treatment

Surgery ☐ Yes ☐No
Surgery Date(s) (year):
Surgical procedure/location/findings:
Radiation ☐ Yes ☐No
Body area treated:
End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) ☐ Yes ☐No

Names of Agents Used	End Dates (year)

Persistent symptoms or side effects at completion of treatment: ☐ No ☐ Yes (enter type(s)) :

Familial Cancer Risk Assessment

Genetic/hereditary risk factor(s) or predisposing conditions:
Genetic counseling: ☐ Yes ☐ No
Genetic testing results:

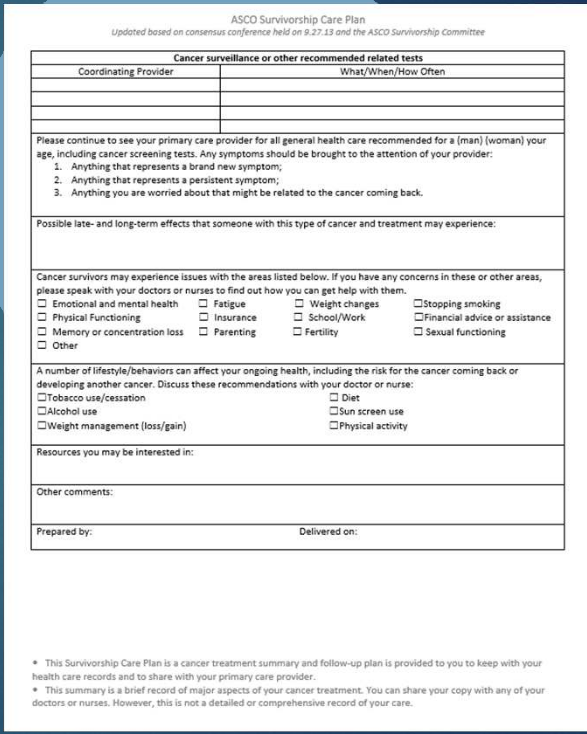
Follow-up Care Plan

Need for ongoing (adjuvant) treatment for cancer ☐ Yes ☐ No

Additional treatment name	Planned duration	Possible Side effects

Schedule of clinical visits

Coordinating Provider	When/How often



ASCO Survivorship Care Plan

Updated based on consensus conference held on 9.27.13 and the ASCO Survivorship Committee

Cancer surveillance or other recommended related tests

Coordinating Provider	What/When/How Often

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

☐ Emotional and mental health
☐ Physical Functioning
☐ Memory or concentration loss
☐ Other
☐ Fatigue
☐ Insurance
☐ Parenting
☐ Weight changes
☐ School/Work
☐ Fertility
☐Stopping smoking
☐Financial advice or assistance
☐ Sexual functioning

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

☐Tobacco use/cessation
☐Alcohol use
☐Weight management (loss/gain)
☐ Diet
☐Sun screen use
☐Physical activity

Resources you may be interested in:

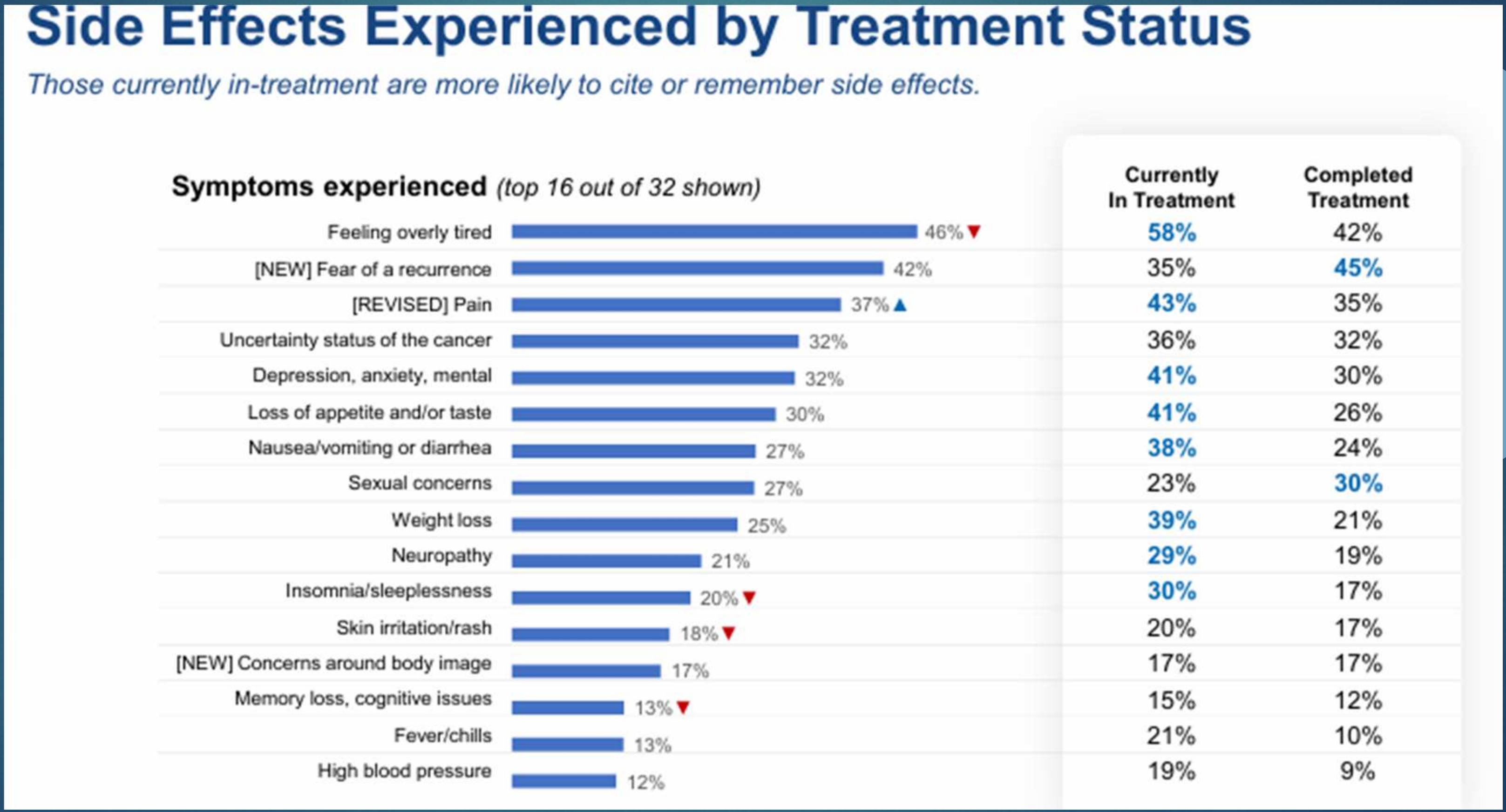
Other comments:

Prepared by:
Delivered on:

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan is provided to you to keep with your health care records and to share with your primary care provider.
- This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your doctors or nurses. However, this is not a detailed or comprehensive record of your care.

https://www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html

National Coalition for Cancer Survivorship (NCCS) State of Survivorship Survey 2024[2]



Side Effects Experienced by Treatment Status

Those currently in-treatment are more likely to cite or remember side effects.

Symptoms experienced *(top 16 out of 32 shown)*		Currently In Treatment	Completed Treatment
Feeling overly tired	46% ▼	**58%**	42%
[NEW] Fear of a recurrence	42%	35%	**45%**
[REVISED] Pain	37% ▲	**43%**	35%
Uncertainty status of the cancer	32%	36%	32%
Depression, anxiety, mental	32%	**41%**	30%
Loss of appetite and/or taste	30%	**41%**	26%
Nausea/vomiting or diarrhea	27%	**38%**	24%
Sexual concerns	27%	23%	**30%**
Weight loss	25%	**39%**	21%
Neuropathy	21%	**29%**	19%
Insomnia/sleeplessness	20% ▼	**30%**	17%
Skin irritation/rash	18% ▼	20%	17%
[NEW] Concerns around body image	17%	17%	17%
Memory loss, cognitive issues	13% ▼	15%	12%
Fever/chills	13%	21%	10%
High blood pressure	12%	19%	9%

https://canceradvocacy.org/2024-state-of-cancer-survivorship-survey/

NCCS

Well known treatment side effects

Neuropathy

- Multiple drugs may lead to this: platinum (oxiplatin), taxanes (docetaxel), vinca alkaloids (vincristine), myeloma treatments and others
- May lead to disability and significant pain
- Typical neuropathy treatments utilized

Cardiac

- Cardiotoxic treatments: anthracycline analogues (doxorubicin, epirubicin), HER-2 targeted agents (trastuzumab), radiation therapy, hematopoietic cell transplantation, antiangiogenic agents, and immune checkpoint inhibitors
- Childhood cancer survivors are at particular risk

Hair loss

- Not all chemotherapy causes hair loss, but the list is too extensive to list here
- Cold capping is an approach to prevent with varying success

Less discussed, but common side effects

Mental Health

- Increased risk of major depression and other psychiatric disorders such as anxiety, insomnia, adjustment disorders, PTSD, etc
  - Around ⅓ of cancer patients will also have at least 1 comorbid psychiatric disorder[15]
- Differentiate between normal reaction to life-threatening illness vs psychiatric disorder vs effect of cancer or treatment
- Suicide ideation is comparable to general population, but suicide attempts and deaths are higher in cancer patients[15]
  - Risk of dying by suicide 26% higher than general population. Absolute risk remains small.[15]
  - Risk is highest after initial diagnosis (within 1 week)

Less discussed, but common side effects

Sexual Health

- Many treatments will induce menopause for women
- Some differences in effects based on gender[16]
  - Women struggle most with vaginal dryness and libido
  - Men tend to have problems with erection, ejaculation and orgasm
- Important aspect to quality of life that is not always addressed

Fertility

- Study showed 73% of female young adult cancer survivors felt they did not receive enough information regarding fertility preservation options at diagnosis[17]

Less discussed, but common side effects

"Chemo brain" or cancer-related cognitive impairment (CRCI)

- Prevalent but poorly understood etiology
- Up to 75% of cancer patients report some form of CRCI during treatment, and it is still present many years after treatment in 35%[18]
- Behavioral interventions have more data to support, but some are trying stimulants (modafinil) or donepezil

Fatigue

- Still most reported side effect in 2024 survivorship survey[2]
- Multiple potential etiologies: treatment side effect, anemia, emotional disturbance and sleep disturbance
- Still do the usual fatigue lab work up

Less discussed, but common side effects

Financial strain

- 2024 NCCS Survivorship Survey over 40% of all patients experience financial sacrifice, 90% of those aged 18-39 years old[2]
- May have long lasting impact on school/career
- 9-10% delay purchases or events or need assistance with prescriptions, food or housing [2]

Relationship strain

- 2001-2006 study on partner abandonment in serious medical illness showed no overall increase in divorce rate (11.6%), but 20.8% if woman affected partner and 2.9% if man affected partner[19]
- Common stories about getting ghosted by family and friends in support/online groups

Don't forget about the caretakers!

Extra considerations for certain populations

Metastatic disease

- More likely to experience side effects
- Goal of care and definition of quality of life can be very different patient to patient
- Consider second opinion at tertiary center to have access to clinical trials
  - 74% of patients who didn’t participate in clinical trials said it was because they were not asked (NCCS Survey 2024)[2]

AYA (adolescent, young adult) or CAYA (children, adolescent, young adult)

- Increased affect on mental health, financial support, sexual health and support systems

Rare cancers

- Harder to find research, support groups and information

Don’t forget about lifestyle interventions

Lifestyle interventions important to address side effects and to reduce risk of progression/recurrence

- Weight and nutrition
- Exercise
- Smoking
- Alcohol intake
- Sleep
- Stress management

My recommendations to improve survivorship care

- RE-EVALUATE THE LANGUAGE USED WITH YOUR CANCER PATIENTS
- FIND OUT WHAT SURVIVORSHIP RESOURCES ARE AVAILABLE IN YOUR AREA
- CULTIVATE COMMUNICATION WITH YOUR ONCOLOGY REFERRAL GROUPS
- ASK ABOUT THE LESS COMMONLY ADDRESSED SIDE EFFECTS
- GAUGE INTEREST IN SECOND OPINIONS
- HELP POINT THEM IN THE RIGHT DIRECTION FOR CLINICAL TRIALS, IF NEEDED
- ACTIVELY CHECK IN REGARDING THEIR SUPPORT AND CHECK FOR RELATIONSHIP STRAINS
- CHECK IN WITH THE CAREGIVERS

How can I add this to my practice

- Awareness is the first step
- Gauge your bandwidth for additional steps
- Educate yourself on survivorship
  - Many UpToDate articles
  - The George Washington University School of Medicine Cancer Survivorship Series (online and free)
    - https://cme.smhs.gwu.edu/gw-cancer-center-/content/cancer-survivorship-series
  - NCCS website and resources
    - https://canceradvocacy.org/resources/tools-for-care-providers/
  - NCCN guidelines and ASCO guidelines
    - ASCO: https://society.asco.org/news-initiatives/current-initiatives/cancer-care-initiatives/survivorship-compendium/care
    - NCCN: https://education.nccn.org/category/disease-area/survivorship
- Speak with oncology referral groups
- Consider starting local survivorship programs or visits
  - Start the conversation
  - Network with other providers
- Consider advocacy within your system and your legislature

> “Courage doesn’t always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow’”
>
> - Mary Anne Radmacher

Questions and Discussion

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