

Supplementary Online Content

Gharzai LA, Resnicow K, An LC, Jagsi R. Perspectives on oncology-specific language during the coronavirus disease 2019 pandemic: a qualitative study. *JAMA Oncol.*

Published online August 6, 2020. doi:10.1001/jamaoncol.2020.2980

eAppendix. Oncology Language for the COVID-19 Pandemic

This supplementary material has been provided by the authors to give readers additional information about their work.

Oncology Language for the COVID-19 Pandemic

Purpose

This document offers oncology providers sample language for communicating changes in delivery of cancer care due to the pandemic of the novel coronavirus of 2019 (COVID-19). It contains:

- 3 general evidence-based communication principles
- Suggestions for addressing specific issues related to the following aspects of cancer care:
 - COVID-specific fears
 - Screening
 - Diagnostic workup
 - Treatment
 - Follow-up
 - Inpatient issues

The suggested language is not intended to be a verbatim script, and practitioners are encouraged to adapt the wording in the hopes it will help us all deal with patient concerns during this difficult time.

Please be aware that **Rogel Cancer Center's Patient Family Support Services is offering well calls for patients showing signs of distress**; information on this and tips for helping patients manage anxiety are available in the [Resources](#) section.

Your Feedback is Important

Please help us make this guide better for cancer care providers and patients.

[Fill out our Qualtrics survey »](#)

We have two quick questions:

- How helpful did you find it?
- What changes would you like to see?

Thank you.

Oncology Language for the COVID-19 Pandemic

Contents

Purpose	1
General Evidence-Based Communication Principles	3
Outpatient Oncology	6
COVID-specific Fears	6
Cancer Screening	6
Diagnostic Workup	7
Initiation of Treatment	8
Non-standard Treatment	9
Treatment Break	10
Follow up	11
Inpatient Oncology	12
Lack of Beds	12
Vital Talk	12
Resources	13
Acknowledgements	14

General Evidence-Based Communication Principles

These 3 Core Communication Principles can help with challenging conversations.

PRINCIPLE 1

The 4Cs. Provide Context, Consideration, Caring, and Commitment

WHAT YOU MIGHT SAY

CONTEXT

Sharing the “Why” to reduce patient distress

“If it’s OK I’d like to try to explain why we are doing things this way [PROVIDE A RATIONALE, WITH SAMPLE LANGUAGE BELOW].”

- We expect/have a surge in people with COVID here in Michigan.
- The number of people needing care will soon be/is greater than our current medical resources (hospital beds, doctors, and medical supplies).
- This has impacted how we are treating our cancer patients during this difficult time
- As more and more COVID patients come into the health system, we need to think carefully about how to:
 - Take the best care of you and optimize your cancer treatment
 - Protect you and others from getting the virus

CONSIDERATION

Highlight your process and show you are thinking about their case

“I have talked with leaders in the Cancer Center and my colleagues and thought hard about your specific case. I (we) think the best plan would be [YOUR RECOMMENDATION]”

CARING

Express concern and share your wishes

Recognize their emotions, using empathetic, reflective statements and express your personal concern.

“It sounds like you’re scared about delaying your treatment. I want you to know that I want what is best for you. While I wish we could have continued our original plan/schedule, I believe this new plan:

- Is a safe/the best way to manage your care over the next few months.
- Will reduce your risk of being exposed to the virus.
- Will help keep your immune system strong while the virus is spreading in the community.

COMMITMENT

Express your commitment to ongoing care and suggest action steps

“Part of the difficulty is the uncertainty of how long this will all last. Through all of this, I will be your doctor and we will work together to get you the best possible care.

- The best way for us to stay in touch would be [YOUR METHOD]
 - The best things you can do to stay safe are... [SEE RESOURCES]
 - The Cancer Center also has more resources... [SEE RESOURCES]
-

PRINCIPLE 2

Use ASK-TELL-ASK to Share Information

Prepare the patient to receive new or difficult information and assess their understanding using the 3-step ASK-TELL-ASK process. This structure invites conversation, supports patient autonomy, and reduces resistance to receiving information.

WHAT YOU MIGHT SAY

ASK	<i>“What have you heard about coronavirus/COVID here in Michigan?”</i> <i>“What information do you need?”</i>	
TELL	<i>“Here’s what I (we) know…”</i>	<i>“Let’s talk about…”</i>
ASK	<i>“What do you make of all this?”</i> <i>“What else do you want to know?”</i>	<i>“What are our next steps?”</i>

PRINCIPLE 3

Recognize and Normalize Emotions

REFLECT PATIENT FEELINGS WITH “YOU” STATEMENTS

“You” statements feel more empathic than “I” statements
 Avoid saying “I understand.” The patient might say, “no you don’t; you don’t have cancer.”
 You don’t always have to fix the problem. Often, just listening with empathy can help.

WHAT YOU MIGHT SAY

You can introduce your reflections with statements such as...	<i>“It sounds like…”</i>	<i>“Correct me if I’m wrong…”</i>
Or start directly with You’re...	<i>“You’re scared because…”</i>	<i>“You’re confused about…”</i>
	<i>“You’re frustrated because…”</i>	<i>“You’re sad because…”</i>
	<i>“You’re wondering if…”</i>	<i>“You’re feeling powerless because…”</i>
NORMALIZE PATIENT EMOTION	<i>“It is normal to be…”</i> <i>“I am (We are) hearing this a lot…”</i>	<i>“Many people are feeling that right now…”</i> <i>“These are difficult times, we expect people are stressed and out of sorts…”</i>

DON’T MINIMIZE THE PATIENT’S CONCERNS

If the patient says “I’m terrified,” don’t reflect with lesser intensity such as “You are concerned”
 Match or exceed the patient’s intensity of emotion
 Try to avoid blanket reassurance like “It will be OK,” unless you’re certain this is true

Examples of Reflective Responses for Intense Emotion

Adapted from VitalTalk

WHAT THEY SAY	WHAT YOU MIGHT SAY
I'm scared...	You're frightened and that's normal given what's going on. Right now the best thing we can do...[SUGGEST A PRACTICAL STEP].
It's not fair...	You're upset with the change in your cancer treatment. If it would be helpful I'd like to explain why we decided to change your treatment plan. You're right. This does not feel fair and it's making you mad. I just want to share that all of us—clinic leaders, doctors, nurses, patient and community representatives—are working together to do the best we can for everyone.
You have no right to do this...	You're angry about how this has impacted your cancer care. This is a time where I wish we had more resources for every single one of our patients. If it would be helpful I'd like to explain why we changed your treatment plan.
I want to talk to your boss.	You're upset with me/us. I will ask our director/chief to talk with you. It may take a while to arrange. Is there anything I can do until then? What's the most important thing you need now?
Why is my life not important? Cancer kills too!	You're angry that we have prioritized taking care of COVID over other conditions, particularly yours, and that feels unfair. If it's okay with you I'd like to try and explain why we are doing things this way...
You people are incompetent!	<ul style="list-style-type: none">• You're angry about your experience with us• You're pissed off that we haven't met your needs• You are upset with how you have been treated here• It feels like we aren't hearing your concerns.• You have every right to feel angry.



Outpatient Oncology

COVID-specific Fears

When oncology patients have specific questions or concerns about infection with COVID.

WHAT THEY SAY	WHAT YOU MIGHT SAY
<p>Should I be more worried about the virus because of my history of cancer?</p> <p>Am I going to do worse if I get infected because of my history of cancer?</p>	<p>It is natural that you are worried. People with cancer, who are older (over 60), and who have other medical problems seem to be at higher risk of complications from COVID. That's why it's important for you and those around you to practice good hand washing and avoiding contact with others as much as possible. What other questions do you have?</p>
<p>How will COVID affect my ability to get care from you?</p>	<p>We are committed to you during this challenging time. Our cancer center is moving to more telephone and video visits to make sure that we are taking good care of our patients while minimizing your risk of being exposed to the virus.</p>

Cancer Screening

Some patients may be asked to delay screening for new cancers, such as colonoscopies in the absence of known colon cancer or low dose CT for lung cancer screening in the absence of known lung cancer.

WHAT THEY SAY	WHAT YOU MIGHT SAY
<p>What happens if I can't get my test for a while?</p>	<p>You're worried that delaying your testing might be harmful. The usual timing for your screening [TEST] is once every [TIME INTERVAL]. So a delay of a few months should not be a problem. Delaying your test could also help reduce your risk of exposure to the virus. We will stay in touch and get this scheduled as soon as we can after this crisis is over.</p>
<p>What if I have cancer and you don't catch it in time because of this delay?</p>	<p>Cancer is scary and the thought of not finding it can be worrisome. However, this screening test is specifically to catch early cancers. I expect that we'll be able to get this test done in the next few months so this should not be a problem for you. Delaying your test could also help reduce your risk of exposure to the virus since we are expecting more and more people with COVID to be coming in.</p>
<p>Can I go somewhere else?</p>	<p>You're welcome to discuss your care with anyone. However, my understanding is that most health systems, especially here in Michigan, are rescheduling cancer testing and treatment as they deal with the COVID crisis.</p>
<p>How long is it going to take before you can test me?</p>	<p>The uncertainty of how long COVID will last is part of the difficulty. I'm hopeful that we'll get through the worst of this in the next few months. We will stay in touch and get this scheduled as soon as we can after this crisis is over.</p>

Diagnostic Workup

When diagnostic workup for a new cancer must be deferred, such as PET scan for suspected metastatic cancer, or bronchoscopy for suspected lung cancer.

WHAT THEY SAY	WHAT YOU MIGHT SAY
<p>Is my cancer going to kill me if we have to wait for this testing?</p> <p>What if my cancer spreads or gets worse while you do nothing?</p>	<p><i>You're frustrated about having to wait. We are trying to balance:</i></p> <ul style="list-style-type: none"><i>• the need to take the best possible care of you and your current health issues</i><i>• the need to protect you from the virus</i><i>• the need to care for large numbers of new patients with COVID</i> <p>There is no easy answer, but this is best we can do right now (given new health system rules).</p>
<p>How long is it going to take before I can get the test?</p>	<p><i>You want to keep things moving and that's normal. I'm hopeful that we'll get through this difficult time in the next few months. We will stay in touch and get this scheduled as soon as we can after this COVID crisis is over.</i></p>
<p>Does this mean I won't get treatment until this test is done?</p>	<p><i>You are anxious to get started with treatment and that is natural. Unfortunately, we need to have all the information before we can decide on the right treatment. Because of the COVID crisis, we'll probably have to wait a few months to get the test done. We will stay in touch and I will work with you to get this done as soon as we can after the crisis is over.</i></p>
<p>Why is COVID considered more critical than cancer?</p>	<p><i>It sounds like you're frustrated and feel like your care isn't a priority. These are extraordinary times. A year ago, none of us would have dreamed of having conversations like you and I are having right now. We are trying to do the best we can to balance taking care of you and protecting you from the virus while dealing with a large number of new COVID patients. There is no easy answer.</i></p>

Initiation of Treatment

When patients must delay the initiation of definitive or palliative therapy.

WHAT THEY SAY	WHAT YOU MIGHT SAY
<p>Isn't it important to treat cancer as soon as it is discovered?</p> <p>Will this hurt my chance for cure?</p>	<p><i>Cancer is scary and it's natural to feel like you need to do something right away. For some cancers, it can be okay to wait a little while to start treatment.</i></p> <p><i>With so many COVID patients coming to the hospital and clinic, we want to balance the need to treat your cancer with the need to keep you safe at home. I think overall it would probably be safer to wait a bit before starting your treatment.</i></p>
<p>I can't handle knowing this cancer is inside me—why aren't we doing anything?</p>	<p><i>It's incredibly hard for you to know you have cancer and for us to be holding off treatment. We are having a health care crisis right now like I have never seen before. I am committed to giving you the best possible care and we will absolutely get/keep going with your treatment as soon as we are able.</i></p>
<p>If I have a deadly cancer, why do patients with coronavirus get priority over me?</p> <p>Why is my life not important enough to save? Cancer kills too!</p>	<p><i>You are really frustrated and feel you are not being treated fairly. We are having a health care crisis and this is certainly a time when I wish we had more resources for every one of our patients. We are trying our best to be fair and use the resources we have to take the best care of everyone. We will absolutely get/keep going with your treatment as soon as we are able.</i></p>
<p>Is the cancer going to grow while you wait?</p>	<p><i>It sounds like you're worried about the cancer growing before we start/resume treatment. We are trying to balance:</i></p> <ul style="list-style-type: none"> • <i>the need to treat your cancer</i> • <i>the need to protect you from the virus</i> • <i>the need to care for large numbers of new patients with COVID</i> <p><i>There is no easy answer. But overall, I think a wait of a few months probably will not affect the course of your cancer treatment and could help reduce your risk of catching the virus.</i></p>

Non-standard Treatment

When patients are asked to undergo a less-than-ideal treatment for their cancer due to resource constraints, such as deferring chemotherapy and treating with radiation alone during what would normally be a chemoradiation treatment plan, or foregoing surgery and treating with chemoradiation when normally patients would receive definitive surgical management.

WHAT THEY SAY

How do you know this different treatment will work?

Will I die sooner because you can't give me the proper treatment?

I feel like you're not giving me the best treatment you can.

WHAT YOU MIGHT SAY

*It sounds like you're concerned that this change in treatment will not work as well. Unfortunately, the health care system is under tremendous strain because of the COVID crisis, and we are just not able to do [TREATMENT DROPPED] right now. **Rather than wait, I think it would be best to go ahead with some treatment, which is why I recommend [TREATMENT RECOMMENDED].***

*You are worried we're not giving you the best possible care. At this point, while there are so many other people around with COVID, **we're balancing the risks of:***

- *changing to a different cancer treatment vs.*
- *making you come to the hospital for treatment or potentially suppressing your immune system*

We think this [RECOMMENDED TREATMENT] option offers the best way forward with your care.

Treatment Break

When patients must take a break during treatment due to COVID-19 exposure, resource scarcity, or other issues.

WHAT THEY SAY

What alternatives do I have? Can I go to another hospital?

Am I more likely to have my cancer come back if I have to take a break from treatment?

I feel abandoned.
You're handing me a death sentence.

WHAT YOU MIGHT SAY

*You are welcome to discuss your care with anyone. However, **my understanding is that most health systems, especially here in Michigan, are also very strained right now** trying to take care of large numbers of new patients with COVID.*

These are extraordinary times that are putting incredible strain on all parts of the health care system. I want you to know that I'm committed to giving you the best possible care. We will absolutely get started again with your treatment as soon as we are able.

You're worried that the treatment break will increase your chances of recurrence. And you're right that we don't know for sure how this treatment break will impact things.

*However, **we think that for most patients with your type of cancer, taking a short break from treatment will not be a problem.** And I am concerned that coming in for treatment and the effect of the treatment on your immune system could increase your risk of exposure and complications from COVID.*

In weighing the risks and benefits, we think the best plan is to take a short break.

*You're upset and feel we are not taking care of you since we are not giving you the care that you expected. **We are having a health care crisis due to COVID. I wish we had more resources for every patient.** But because of demands on the health system, we are just not able to do [TREATMENT STOPPED] right now.*

*I want you to know that I'm committed to give you the best possible care. **We will absolutely get started again with your treatment as soon as we are able.***

Follow up

When patients have completed treatment for cancer (recently or not) and are asked to defer follow up imaging, procedures, or visits.

WHAT THEY SAY

What if my cancer comes back and you don't catch it?

WHAT YOU MIGHT SAY

*You're scared the delay in your surveillance testing will cause us to miss your cancer coming back. You're right that we can't know for sure, but **usually a short break of a few months will not affect your overall course.***

*I'm also worried that **now is not the best time for people to come in for tests when we are dealing with so many patients with COVID.** Overall, it probably makes sense to reschedule for now. We'll get back on track with your surveillance as soon as we can after this crisis is over.*

You're leaving me to deal with this alone.

You're upset that we are not taking care of your needs. You feel we are abandoning you and that's scary. I want you to know that I am committed to giving you the best possible cancer care.

***Even if we are not seeing each other in person, there are many ways for us to stay in touch.** This includes phone and video care and support from our Cancer Center team. And we will absolutely get back to your regular care as soon as we are able.*

Inpatient Oncology

Lack of Beds

When patients can't be admitted for more routine or non-COVID reasons, or escalated to a higher level of care in a different unit due to lack of beds.

WHAT THEY SAY

Why do you get to choose who lives and who dies?

Why isn't my life as valuable as the life of someone with COVID?

I'm going to die because of you.

WHAT YOU MIGHT SAY

You feel like we are treating other people's lives as more important than yours. *If it's okay with you, I'd like to explain why we are doing some of these things...*

This is an extraordinary time. We are having a health care crisis due to COVID and are trying to use resources in a way that is fair for everyone. *You are right that we might be having a very different conversation if this were a year ago. But right now [CURRENT TREATMENT PLAN] is the best that we can do.*

You're angry that we have to move you (or discharge you) due to COVID. If it's okay with you I'd like to explain why we are doing things this way.

We are trying to balance:

- *the need to take the best possible care of you and your current health issues*
- *the need to protect you from the virus*
- *the need to care for large numbers of new patients with COVID*

There is no easy answer. But overall we think it makes the most sense to [RECOMMENDED TREATMENT PLAN] *This might not be what either of us wanted, but it is best we can do right now (given new health system rules).*

Vital Talk

For additional inpatient questions that are not oncology-specific, please reference COVID Communication Skills by Vital Talk:

<https://www.vitaltalk.org/guides/covid-19-communication-skills/>

Resources

Rogel Cancer Center Support

For advice on guided imagery, relieving anxiety, music therapy, and support groups for patients, please visit <http://michmed.org/axdmy>.

Your Feedback is Important

Please help us make this guide better for cancer care providers and patients.

[Fill out our Qualtrics survey »](#)

We have two quick questions:

- How helpful did you find it?
- What changes would you like to see?

Thank you.

Acknowledgements

This document was inspired by the practical inpatient and COVID-specific advice published by [Vital Talk](#)

ROGEL CANCER CENTER

DEPARTMENT OF RADIATION ONCOLOGY

Laila Gharzai
Reshma Jagsi
Theodore S. Lawrence

DEPARTMENT OF MEDICAL ONCOLOGY

Christine Veenstra
David Smith

DEPARTMENT OF OTOLARYNGOLOGY

Keith Casper

DEPARTMENT OF SURGICAL ONCOLOGY

Michael S. Sabel

MEDIA TEAM

Nicole Fawcett

PATIENT AND FAMILY SUPPORT SERVICES

Donna Murphy, Cancer Patient Advocate
Network

CENTER FOR HEALTH COMMUNICATIONS RESEARCH

Lawrence C. An	Diane Egleston
Sarah Hawley	Colleen Sullivan Leh
Ken Resnicow	Elizabeth Hershey

MICHIGAN MEDICINE

DEPARTMENT OF INTERNAL MEDICINE

Michelle Heisler

UNIVERSITY HEALTH SERVICE

Marsha Benz

OFFICE OF PATIENT EXPERIENCE

Molly White

OUTSIDE CONTRIBUTORS

CHILDREN'S MERCY HOSPITAL, KANSAS CITY MO

Delwyn Catley
Kathy Goggin

UNIVERSITY OF ROCHESTER, SCHOOL OF MEDICINE

Geoffrey Williams