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Health Communication in the Era of Publicly Available Medical Information and Misinformation

Date: 10/8/2025

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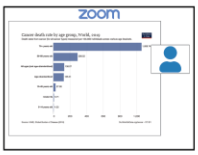

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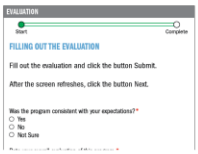

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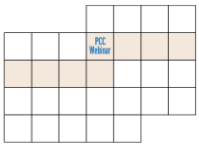

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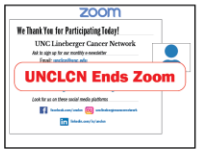

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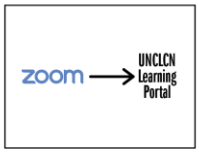

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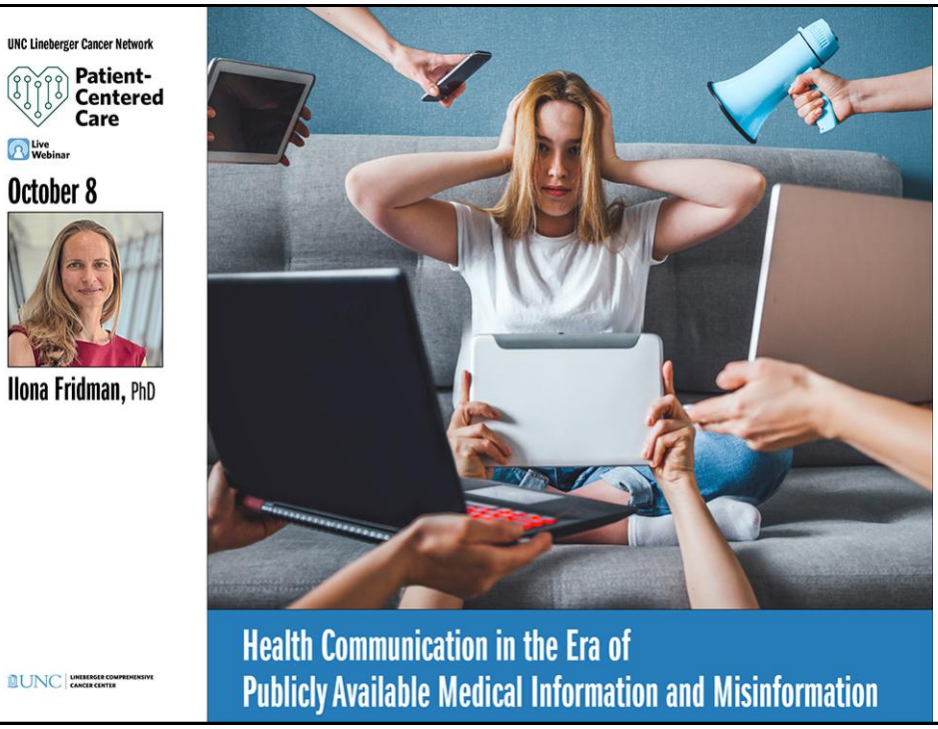

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Our Presenter

Ilona Fridman, PhD

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Our Presenter

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4. Bio Point 4
3. Bio Point 3
2. Bio Point 2
1. Bio Point 1

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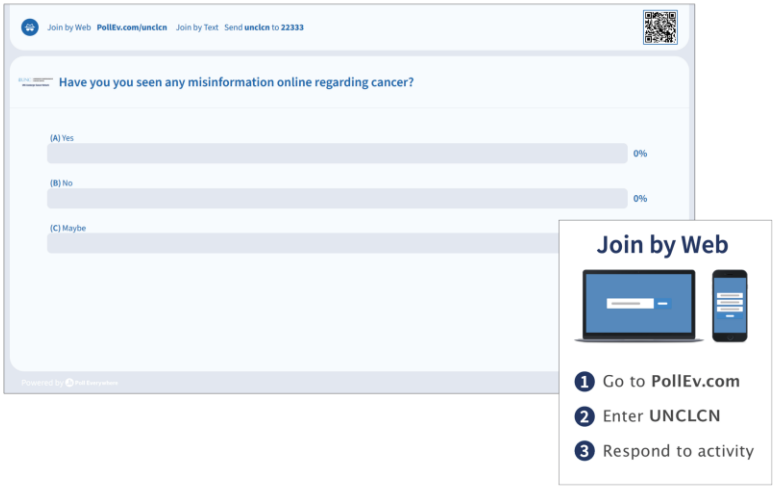
Sample Poll Everywhere Question



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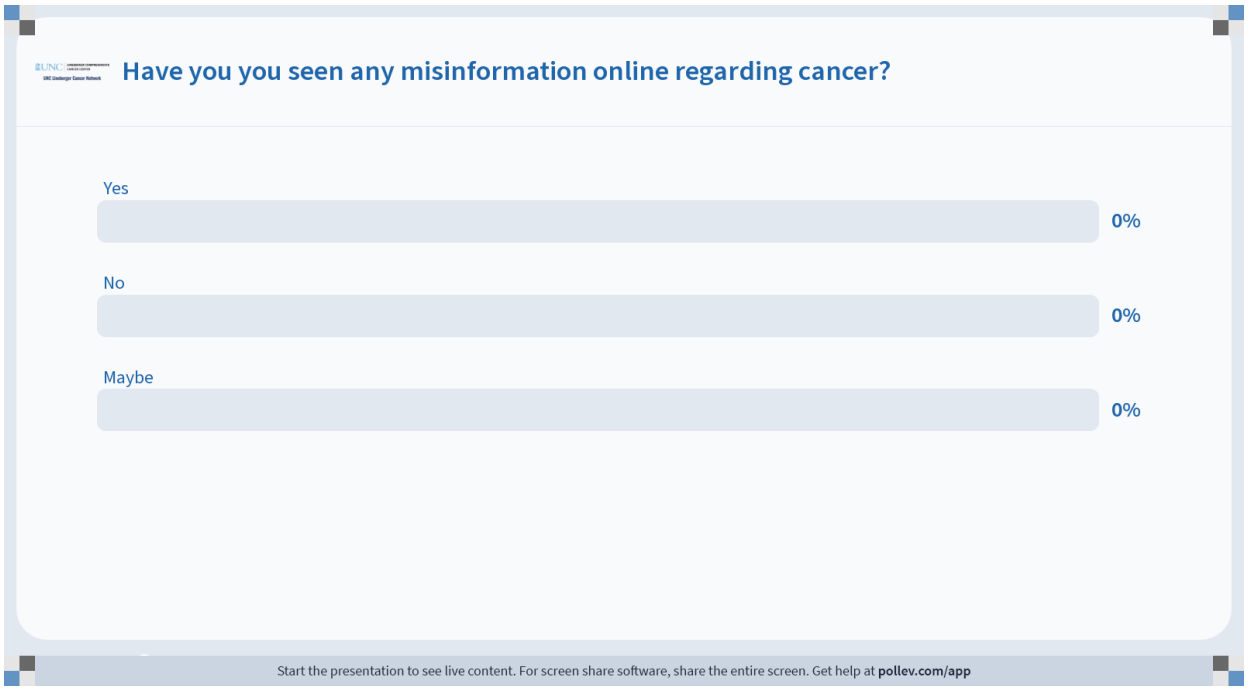

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Health Communication in the Era of Publicly Available Medical Information and Misinformation

Ilona Fridman, PhD,

Assistant Professor at Hackensack Meridian School of Medicine and Georgetown University Lombardi Cancer Center

2025

Hackensack Meridian Health

GEORGETOWN UNIVERSITY
Lombardi Comprehensive Cancer Center

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Psychological burden of misinformation: Interview with a patient

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My provider said I had to eat proteins to recover after chemotherapy. But I saw people going cancer-free after raw food dieting.

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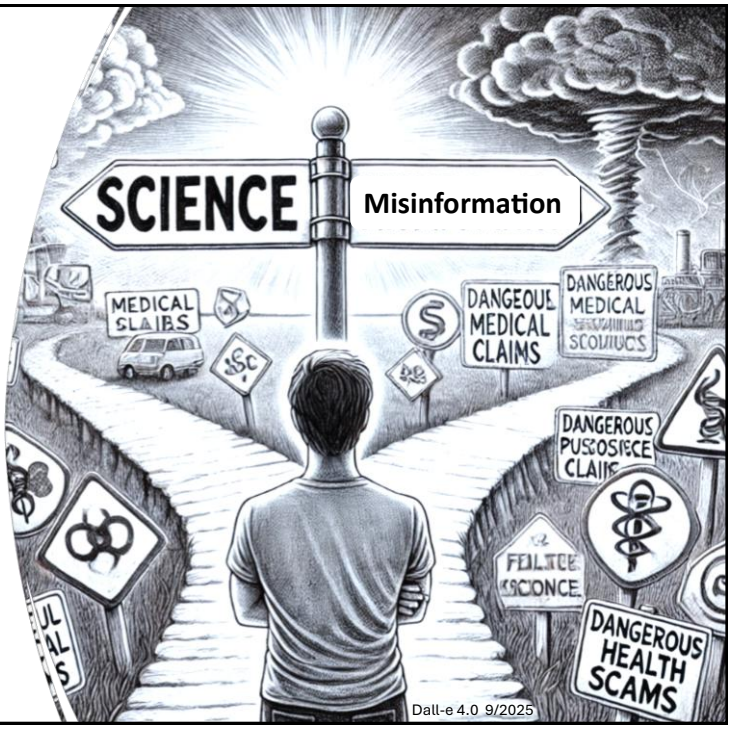
Guiding Research Question

How people perceive information and what they evaluate important and worth acting upon?



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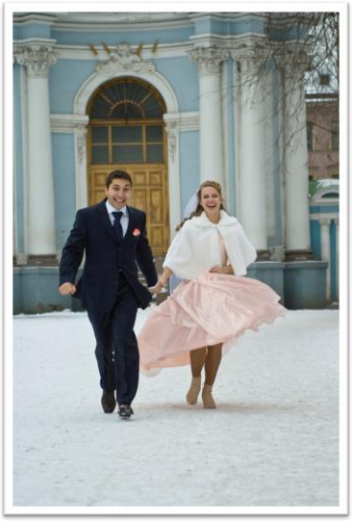
Background



Time. 1987, July 27

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Questions to you:

(Poll Everywhere, n of people who said yes to each question/n of people who answered)

1. Have you encountered misinformation in your practice? (yes/no/I am not sure)

2. Did you feel ineffective in communication? (yes/no/I am not sure)

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18

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Why should we study misinformation?

20

How do People Receive Health Information Today?

- 72% of adults go online first for health information (Health Information National Trends Survey by NCI, 2020)
- 65% of patients with cancer or/and caregivers reported willingness to use social media for medical decisions (Fridman et al., 2024)
  - 61% of White vs. 94% of Black respondents were willing to use social media

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What is the Quality of Information Online?

- 40% of health-related posts in social media contain unreliable claims or misinformation
  (Suarez-Lledo et al., 2021 sys. review)
- Misinformation is more prevalent in posts about prevalent cancers
  - 70% of posts about prostate cancer
    (Loeb et al., 2019, Alsyouf et al., 2019)
  - 51% of posts about breast cancer
    (Wilner et al., 2020)
- 77% of misinformation related to cancer could lead to harmful decisions. (Johnson et. al., 2021)

FDA 2020

22

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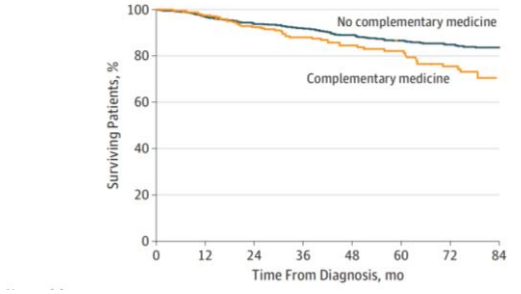
Consequences of Cancer Misinformation

- People who made misinformed decisions about cancer therapies:
  - Decreased adherence to standard therapy (Johnson et al., JAMAOnc 2018)
  - Increased risks of premature death 2.5 times (Johnson et al., JNCI 2018)
  - Experienced financial toxicity: $6.7 millions were raised online for unproven therapy. (Vox et al., 2018, JAMA)
  - Experienced psychological stress (PI interviews, 2015, 2024, 2025)

Figure. Survival of Patients Who Used Complementary Medicine vs Those Who Used No Complementary Medicine for Breast, Prostate, Lung, and Colorectal Cancer



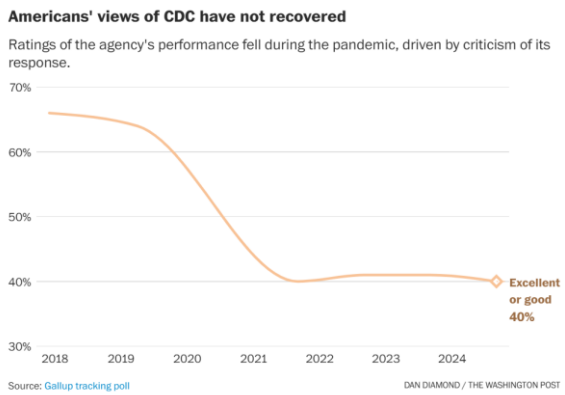
Johnson SB, JAMA Oncol. 2018

23

23

Trust to Science and Scientific Evidence

- The percentage of adults who regarded the Centers for Disease Control and Prevention as “excellent” or “good” fell from 64% to 40% percent. (Shepherd M. The Washington Post. 2025 Jan 12)



- Trust in personal doctors decreased from 93% to 85% (The Independent Source for Health Policy Research, Polling, and News, 2025)
- 40% of people in the US believe that cancer can be treated by natural therapy only (ASCO 2018 Cancer Opinions Survey)

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Objectives of our Conversation Today

- Define misinformation in research and practice
- Examine pathways that lead patients to interact with misinformation
- Utilize evidence-based strategies to address misinformation

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Objective 1: Define misinformation in research and practice

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Questions to you: (Poll Everywhere, word cloud)
In one word, how would you describe misinformation?

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Start the presentation to see live content. For screen share software, share the entire screen. Get help at **pollev.com/app**

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Misinformation can take multiple shapes

Zannettou et al. (2019)	Tambini (2017)	Kumar and Shah (2018)	Wardle and Derakhshan (2017)	Parikh and Atrey (2018)	Tandoc et al. (2017)	Molina et al. (2019)	Lemieux and Smith (2018)	Pamment et al. (2018)	House of Commons (2018)
Fabricated content	Falsehood to affect election results	Misinformation	Satire	Visual based	News satire	False News	Disinformation	Fabrication	Fabrication
Propaganda	Falsehood for profit gain	Disinformation	False connection	User based	News parody	Polarized Content	Hoax	Manipulation	Manipulated content
Imposter	Bad journalism	Opinion based	Misleading content	Post based	Fabrication	Satire	Bias in Fact selection	Misappropriation	Imposter content
Conspiracy theories	Parody	Fact based	False context	Network based	Manipulation	Misreporting	Rumors	Propaganda	Misleading content
Hoaxes	Ideologically opposed news		Imposter content	Knowledge based	Advertising	Commentary	Hyperbole	Satire	False context
Biased or one-sided	News that challenges orthodox authority		Manipulated content	Stance based		Persuasive Information	Misinformation	Parody	Satire
Fallacy			Fabricated content					Advertising	Deep fakes
Rumors			Leaks						
Clickbait			Harassment						
Satire			Hate speech						

Kapantai et al., 2021

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General definition

Misinformation is information that contradicts the consensus of the scientific community regarding a phenomenon at a given time.

(Swire-Thompson et.al, 2020)

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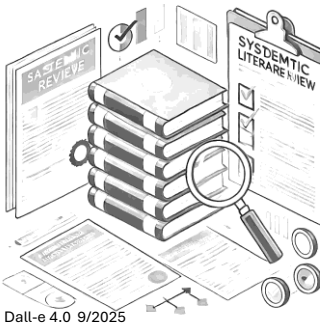
Developing Practical Misinformation Definition

Structured Literature Review

- Searched: PubMed, Cochrane, CINAHL Plus, Embase
- Identified: 1259 articles
- Selected: 13 articles

Characteristics to Detect Harmful Misinformation

- Observable (e.g. motivation is not observable)
- Generalizable (e.g. click bites are not generalizable)
- Simple (no complex logic)



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Fridman et.al., 2023 JMIR Ed

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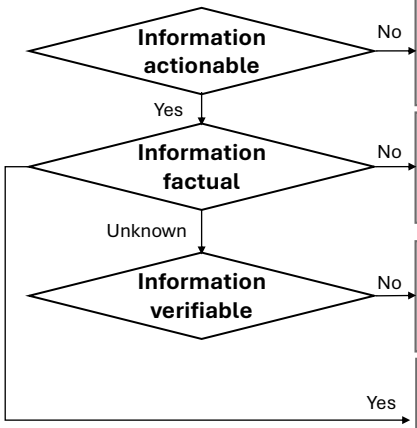
How to Identify Harmful Misinformation?



	Examples	Actions before medical decisions
Information actionable: No	A false cancer diagnosis of a public figure	Discard information as non-impactful
Information factual: No	Starve cancer by removing sugar from your diet;	Note as potentially harmful
Information verifiable: No	High doses of Vitamin C inhibit growth of cancer cells. The effect in humans is unknown	Consult experts about the effectiveness and safety of the discussed therapy
Yes	Patients were nearly 2.5 times as likely to die if they used an alternative therapy instead of standard therapy	Information may be considered to inform medical decisions

Fridman et al., 2025 JMIR infodemic

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How did we apply it?

- **Research question:** Identify cancer misinformation on Twitter.
- **Definition of misinformation**: unproven therapies or substances presented as cancer cure
  - Actionable: Information that can inform decision making
  - Non-Facutal: proven to be ineffective cancer therapies
  - Unverifiable: non-misinformation

Acupuncture can help you to treat cancer pain

Acupuncture can help you to treat cancer

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Types of Cancer Misinformation

Data: X/Former Twitter 45,791 posts about unproven therapies for cancer

Primary results: unproven therapies with the promise to cure cancer (~30%):

- Diet-based approaches 59%
- Alternative medicine systems 32%
- Plant/synthetic-based supplements 31-32%

Diet: *Don't* consume sugar (as cancer thrives on it)

Alternative approach: Create an alkaline environment that cancer can't thrive in! Incorporate herbs, vitamins, and minerals to support your healing journey. You are going to heal

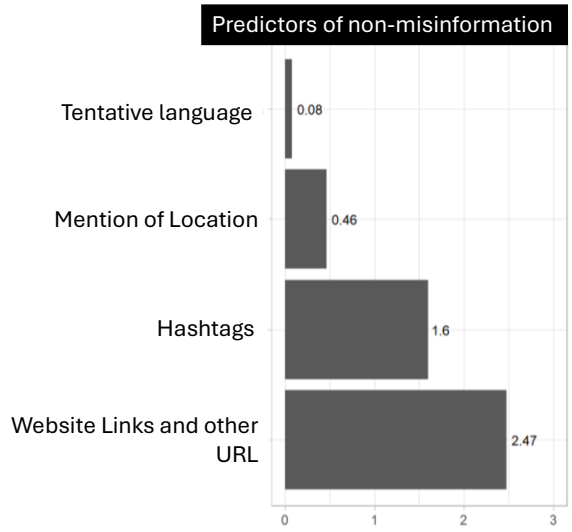
Synthetic-based: Cure for cancer that works holistically, Vitamin B_{17}, *very good!*

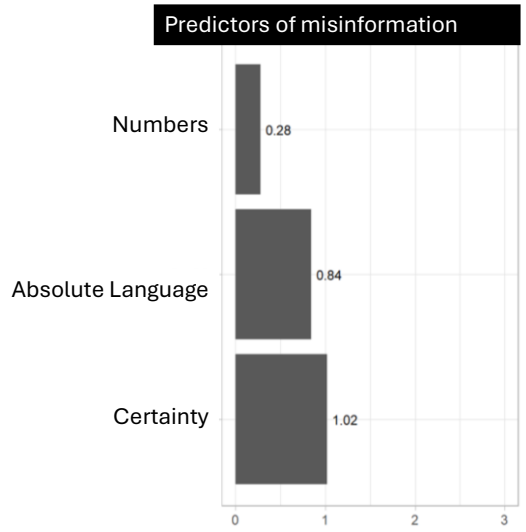
34

Fridman et al., 2025 JMIR infodemic

34

Linguistic Characteristics of Misinformation





Fridman et al., 2025 JMIR infodemic

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Conclusion

- On social media, be careful with confident certain language and presence of numbers without clear citations

Vitamin B17 has **definitely** prevented my cancer from spreading. It's been a while, and there has been no growth.

Cancer is nearly 100% curable, but beware of certain hospital treatments. Explore alternative options for better outcomes.

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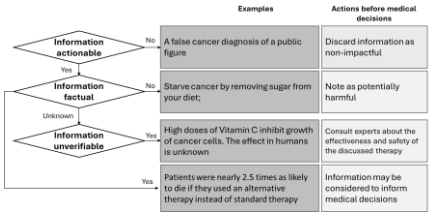
Takeaway message

- Definition of misinformation should be specified for each project and context.
- While encountering misinformation consider
  - Is information actionable?
  - Do we have factual evidence?
  - Acknowledge unverifiability of some information and discuss specific risks that might be associated with it



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Objective 2: Examine pathways that lead patients to interact with misinformation

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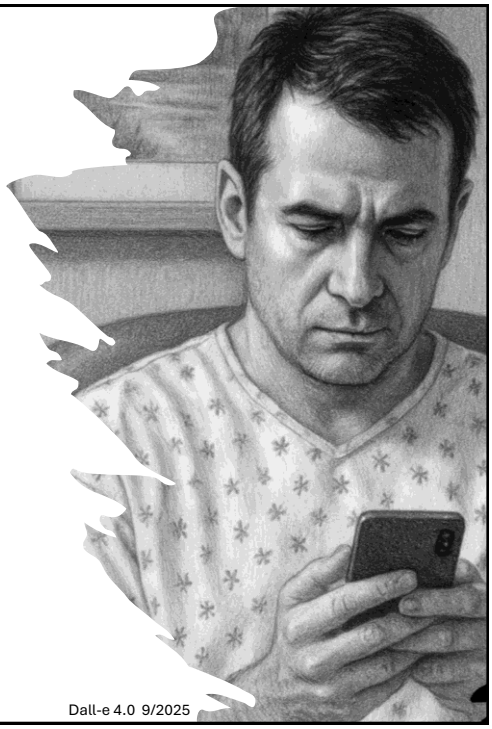
Patient Perspectives

"When I was first diagnosed and leading up to it, I dropped everything I was doing and I spent hundreds of hours doing research, maybe even over a thousand hours." (PC 508)



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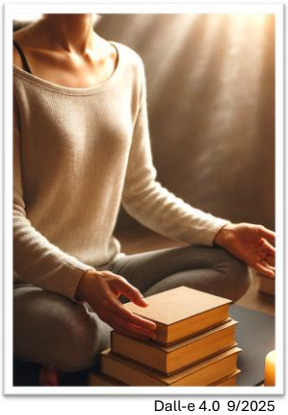
Online Information Can be Beneficial

Patient search for information (online) improves:

- Patient knowledge
- Patient self-care

(Thapa et al., 2021, sys. review)



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Complementary and Alternative Medicine (CAM)

Patients identify complementary medicine that helps with:

- Pain reduction
- Depression and anxiety relief
- Fatigue and body stiffness mitigation
  (Dawczak-Debicka et al.,2022, sys review)

But... Cancer misinformation often appears in CAM, claiming CAM cures or controls cancer.

Overall, 93% (n = 102) of patients with cancer were exposed to at least one form of cancer treatment misinformation (Parket et. al. 2025)

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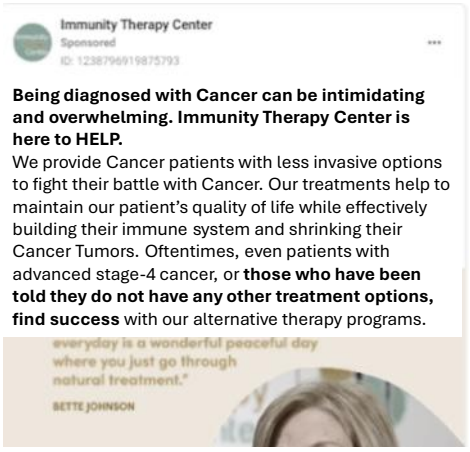
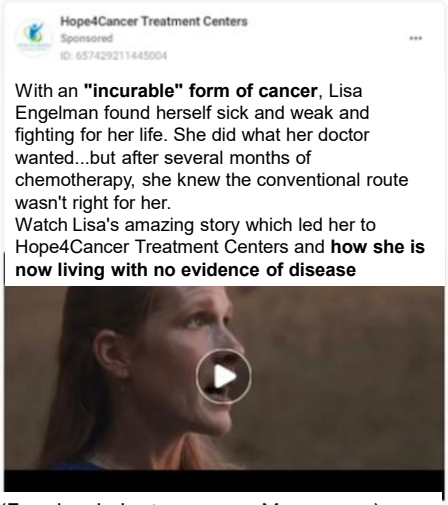
Search for Information Comes with Challenges





310 paid advertisements from 11 alternative cancer clinics on Meta (Facebook, Instagram, or Messenger) marketing alternative treatment approaches, care, and interventions (Zenone et al. 2023)

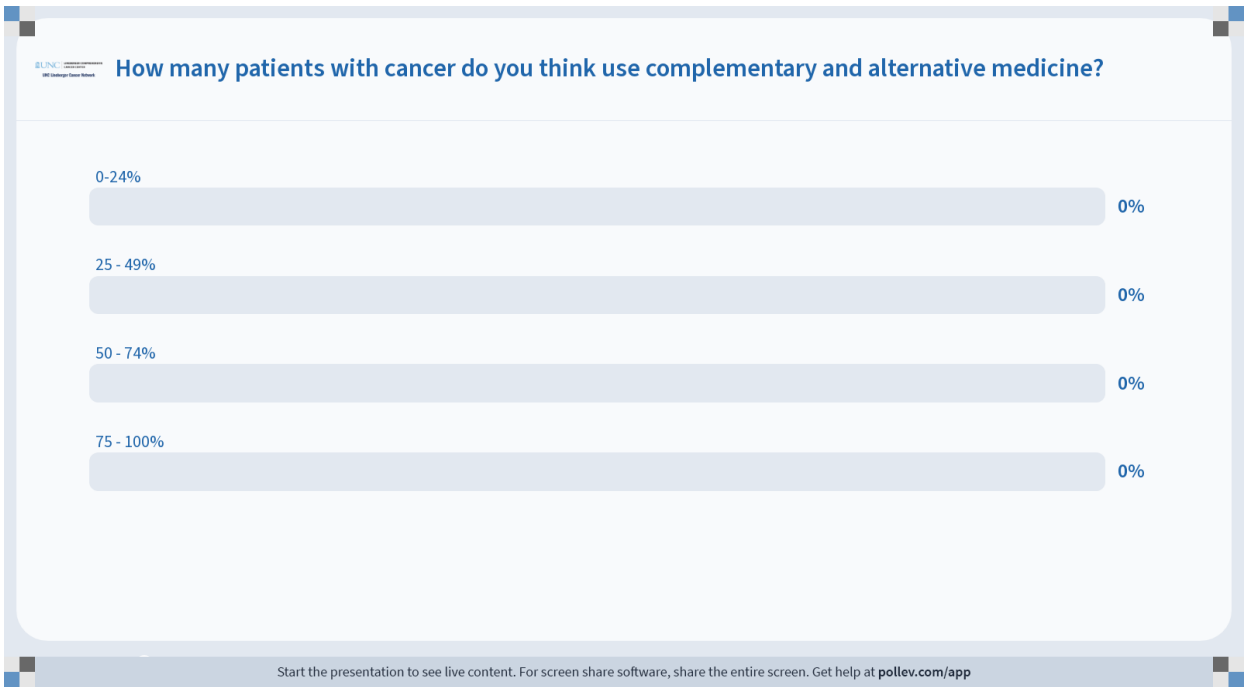
42

Questions to you:

(Poll Everywhere, 100% free range scale)
answer need to show range and average

How many patients with cancer do you think use complementary and alternative medicine?

43



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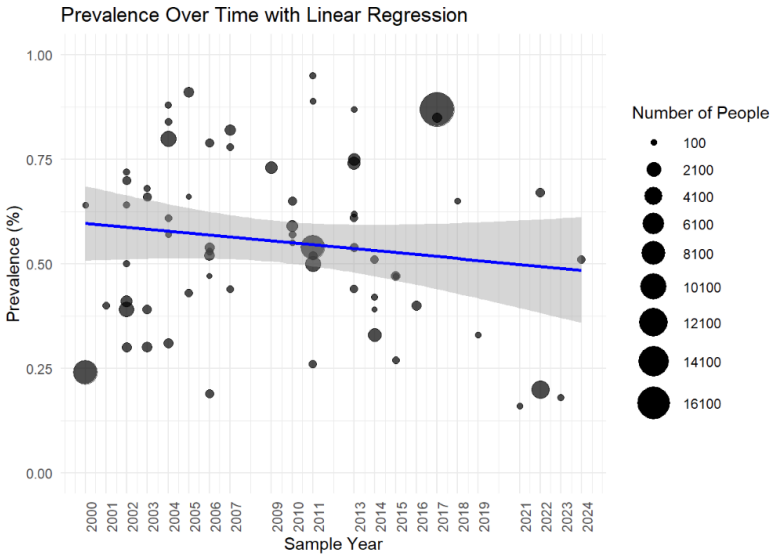
Literature review: Prevalence of using complementary and alternative therapy in the US among oncology patients.



Mean 55%
Range: 16% to 95%

Tsai et al., manuscript in preparation

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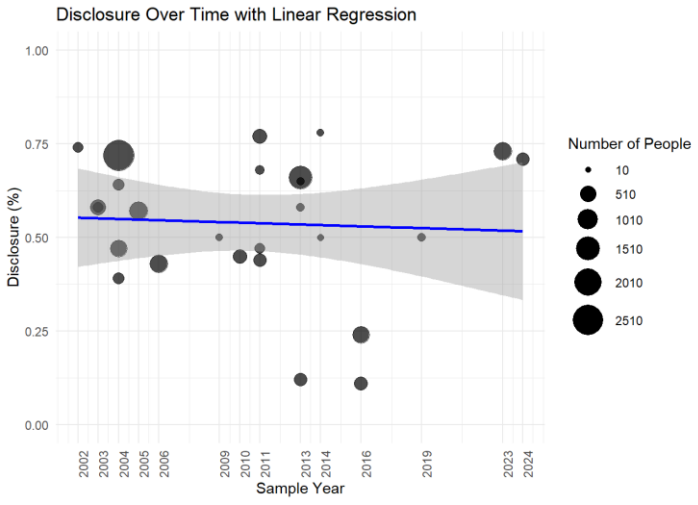
Literature review: Complementary and alternative medicine disclosure to providers



Mean 55%
Range: 11% to 78%

Tsai et al., manuscript in preparation

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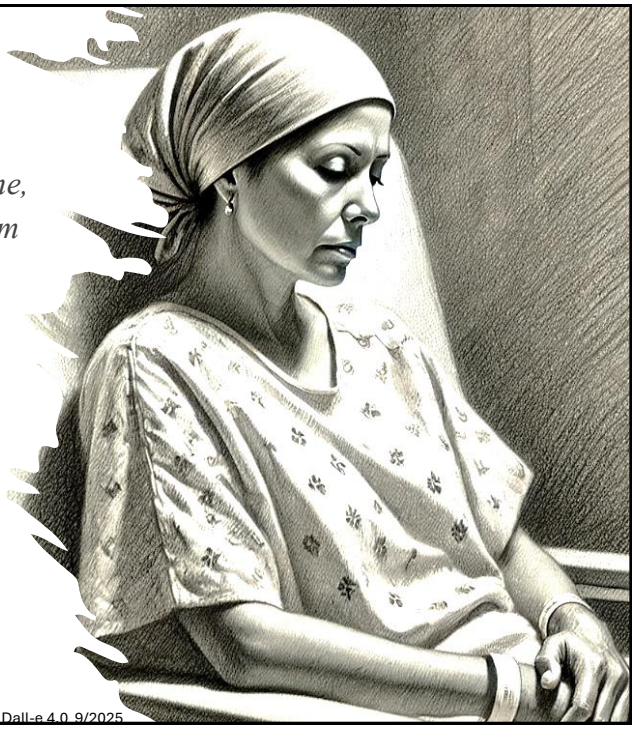
Patient Story: Decisions

They prescribe pill [hormone therapy] for me, but I don't take it. But whenever you tell them that, they want you to take it. And to make a long story short, I just don't tell them. I am constantly taking my herbs, my soursop leaves, my soursop juice.

Some of these contain cancer medicine in there. So I said why not take it straight from out there. When I take the herbs there's no side effect on them. (BC 128)



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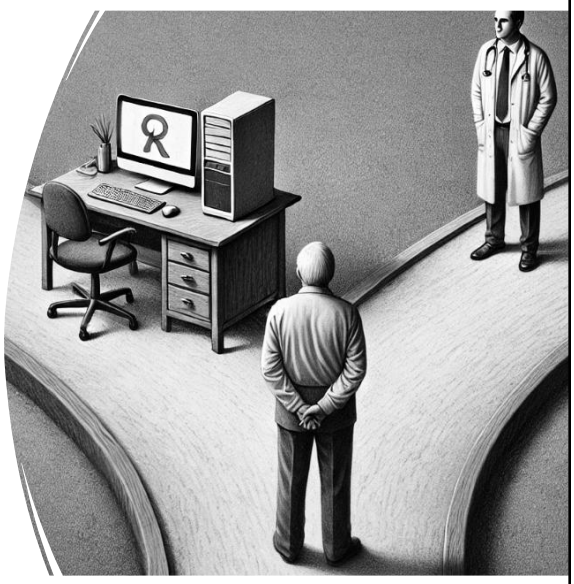
Research Question

How and when patients decide to follow advice from non-clinical information sources instead of providers' recommendations?



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Semi-Structured Online Interviews

Eligibility criteria:

- Patients with breast and prostate cancer
- Interested in complementary medicine
- English speaking
- 21+

Completed study:

N = 19 patients, mean age 58 y.o.

47% Patients with breast cancer

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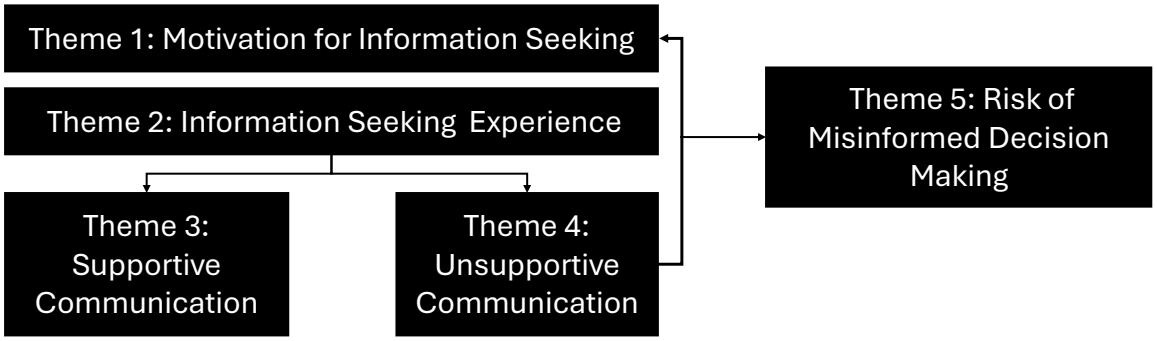
Framework: Patient Information Search and Communication



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Framework: Patient Information Search and Communication

Theme 1: Motivation for Information Seeking

Decision-Relevant Information	Emotion-Relevant Information

"*…when I first met with my [healthcare] team, it was like drinking water from a fire hose with all the information they were giving me. (P508).*"

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Patient Story: Broken Communication

I feel some of doctors were even getting a maybe agitated or angry that I ask a lot of questions "Don't you understand that a person going through the horrific experience and to help lower anxiety you're trying to get as much information as possible. Just to know that information, a little bit ahead of time.

It helps you to calm down. It decreases anxiety to a great amount. And that was missing a lot… I wish doctors would be just more humanly compassionate. (BC 128)

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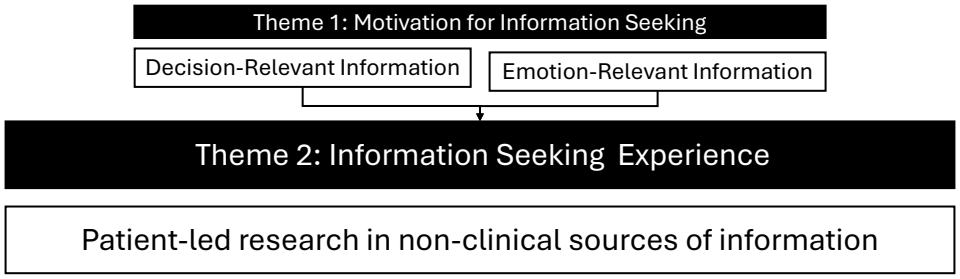
Framework: Patient Information Search and Communication



"I can spend five or six hours a day online, seriously (P56)"

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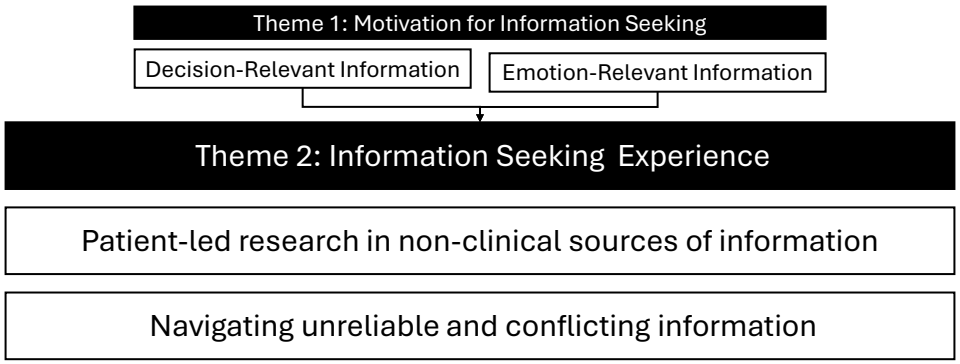
Framework: Patient Information Search and Communication



"I'm not trained in the subject matter to be able to read scientific articles…The main challenge is distinguishing pseudoscience from actual science and deciding whom you trust (PC 423)"

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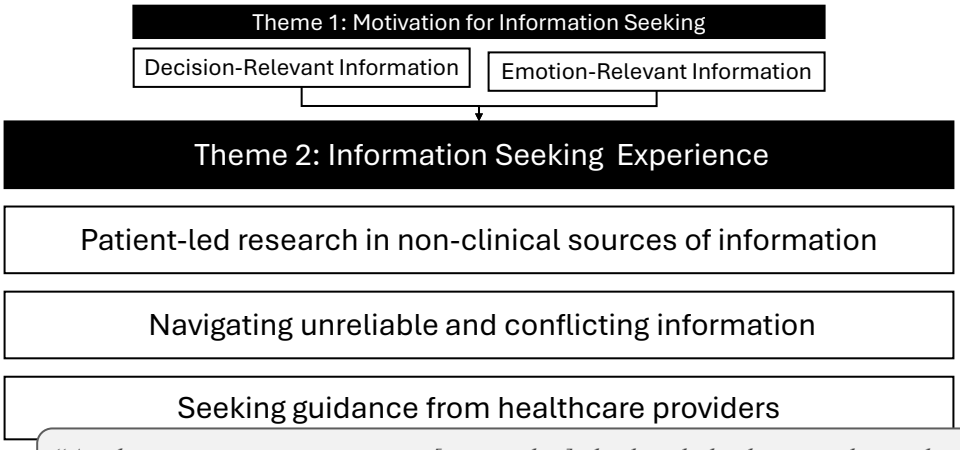
Framework: Patient Information Search and Communication



"Anything you try or want to try to [you need to] check with the doctor with your leading oncologist to make sure it's not going to interfere with the particular treatment (BC 108)."

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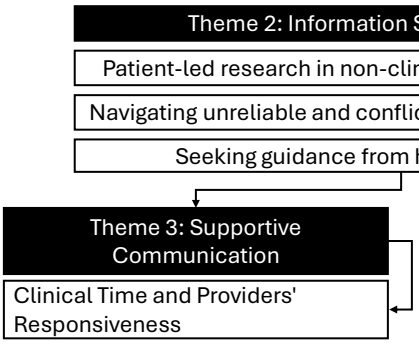
Framework: Patient Information Search and Communication



"I usually walked in with a whole written list of questions. But they were very supportive. Nobody lost patience. The providers kind of liked the idea of answering those questions. (BC 44)"

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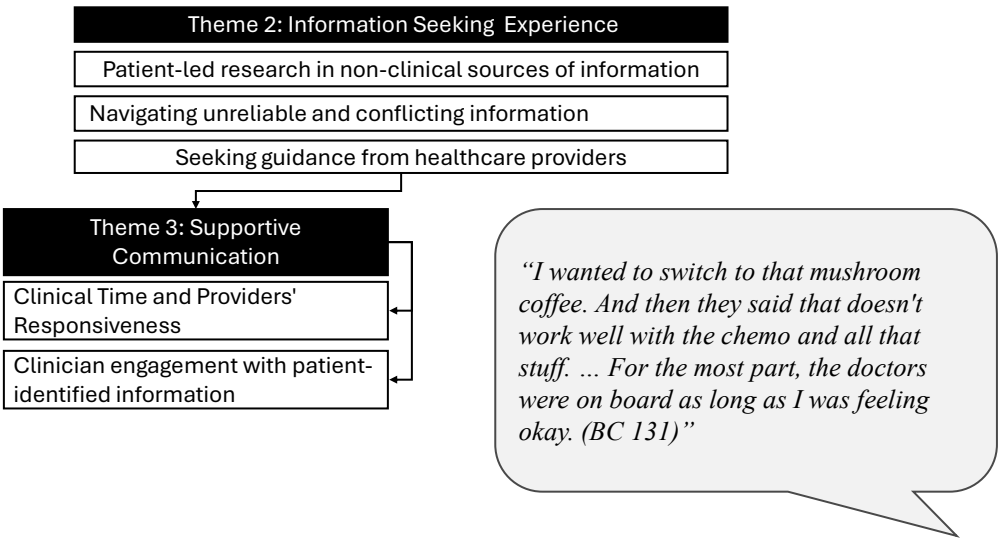

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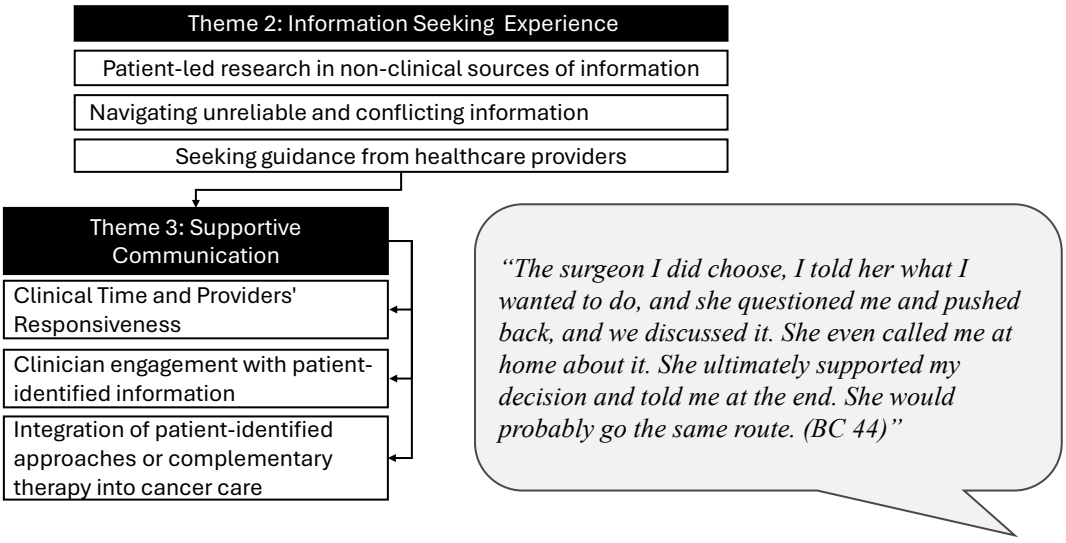

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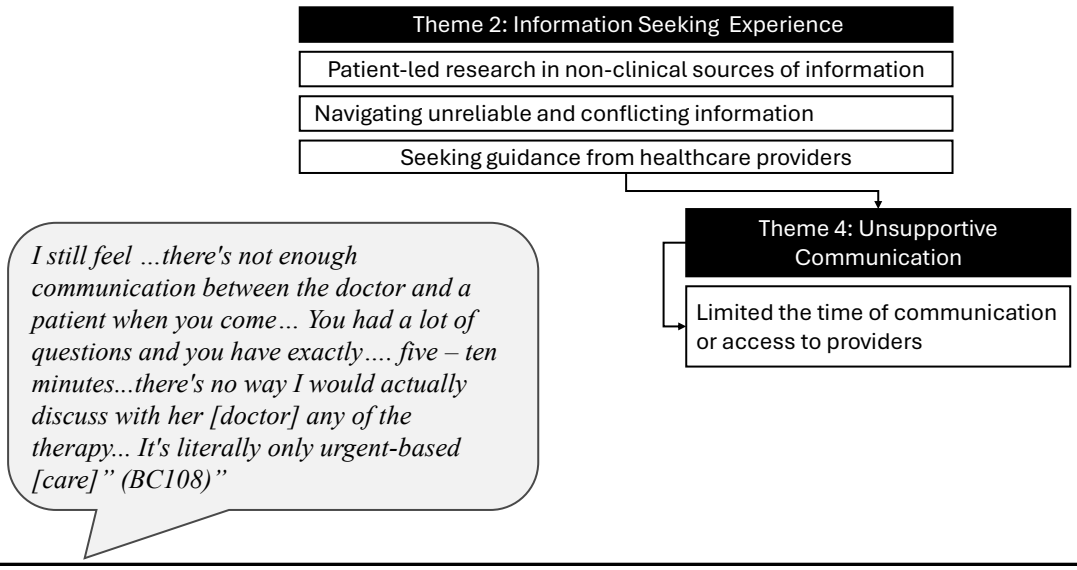

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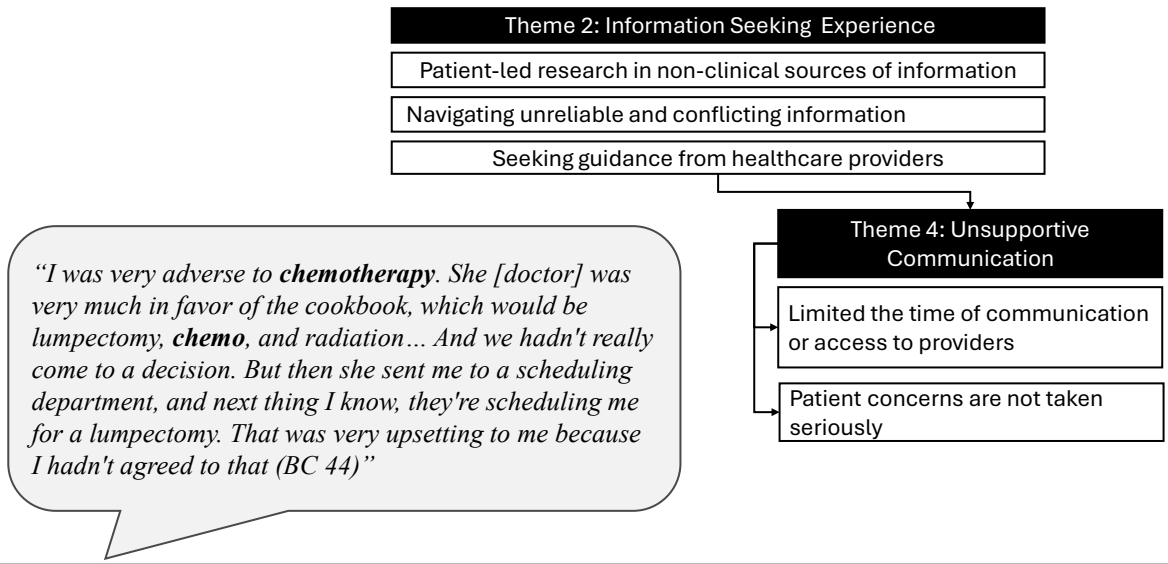

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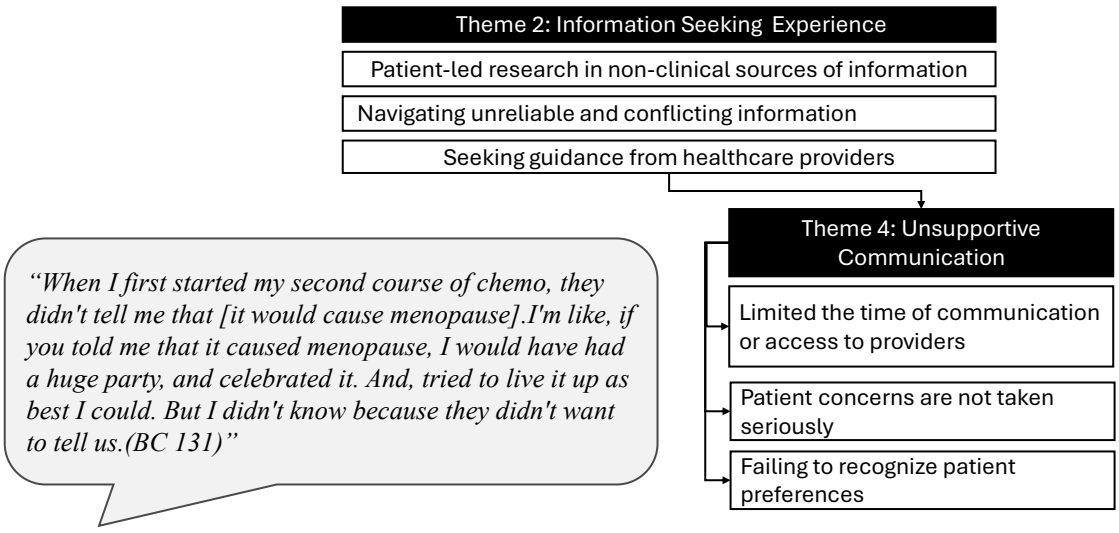

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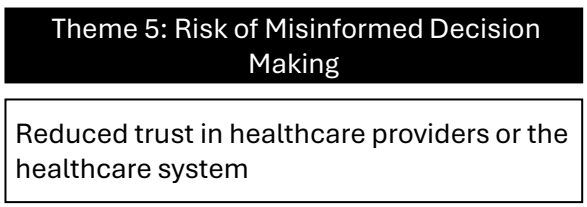
Framework: Patient Information Search and Communication



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Patient Story: Trust

My advice is don't believe the doctor only 50%, or less, because this is business. The sale-person is the doctor. He just have some knowledge about certain things he has learned and that's why he tries to sell them to you. It that's all." (PC 56)

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Framework: Patient Information Search and Communication

Theme 5: Risk of Uninformed Decision Making

- Reduced trust in healthcare providers or the healthcare system
- Relying on the opinion of non-experts

"There was a prostate cancer forum on Facebook, which I found very helpful because it was all gentlemen who had been down the road before me. All with different success rates and…different outcomes and chose different options of treatment (PC153)"

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Framework: Patient Information Search and Communication

Theme 5: Risk of Uninformed Decision Making

- Reduced trust in healthcare providers or the healthcare system
- Relying on the opinion of non-experts
- Non-adherence to clinical recommendations

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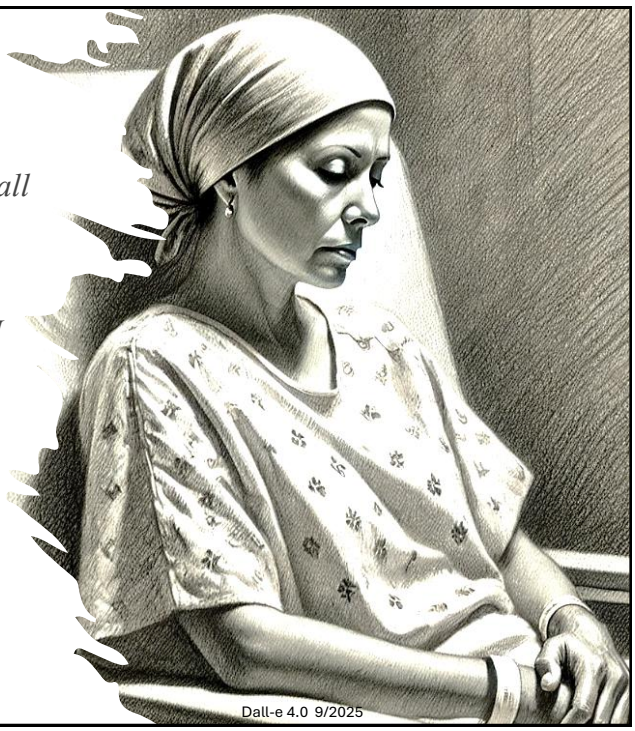
Patient Story: Decisions

"I had read horror stories about tamoxifen all over the internet, and I'm not taking tamoxifen" (BC2024060)"

"I started a holistic treatment for a month. I found a woman in [town], and she got me started on all a lot of the stuff I do still take, but again, I was going as my solo plan." (BC2024060)



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Consequences of Cancer Misinformation

- People who made misinformed decisions about cancer therapies:
  - Decreased adherence to standard therapy (Johnson et al., JAMAOnc 2018)
  - Increased risks of premature death 2.5 times (Johnson et al., JNCI 2018)

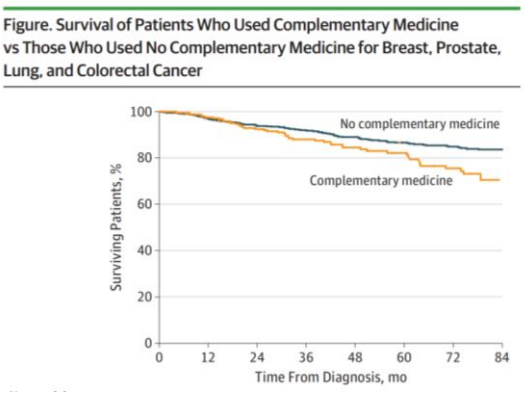

Figure: Johnson SB, JAMA Oncol. 2018

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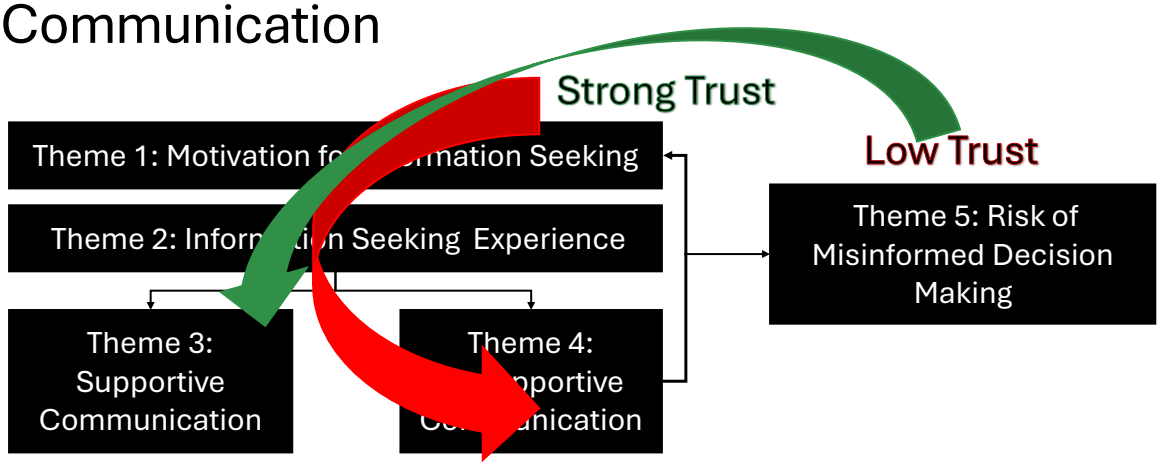
Framework: Patient Information Search and Communication



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Takeaway Message

Supportive communications include:

- Using clinical time mindfully -> Let's discuss in Q&A
- Acknowledging and taking patient information seriously
- Integrating patient-identified therapies could help with maintaining patient trust:

  "I find that if you just say "No" to everything, patients shut down, but if you're willing to compromise on some things, then patients are willing to work with me, they understand."
  (PPC2024002 – advanced nurse practitioner)

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Objective 3: Utilize evidence-based strategies to address misinformation

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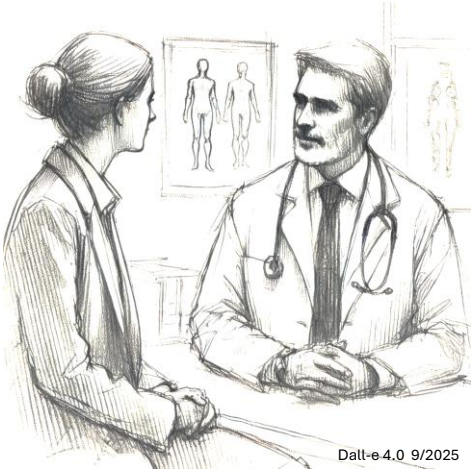
Health Information in Non-Clinical Sources

"I went to this herbal place, and I was talking to the guy. And he said, "Okay, I'm going to give supplements."

"Is it safe? How much to use? When to use it? Does it interact with chemotherapy? Is it going to help with anything else other than, these things, the nausea and fatigue?" (Patient with Breast Cancer)



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Research Question

How providers reacted when patients asked them about information they found outside of the clinical settings?

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Questions to you:

(Poll Everywhere, word cloud)

If a patient brings information they found online to you, in your everyday clinical routine, you usually

a) Redirect the conversation to highlight strong scientific evidence supporting your recommendation.
b) Examine the evidence behind their proposal and explain clearly why it is ineffective.

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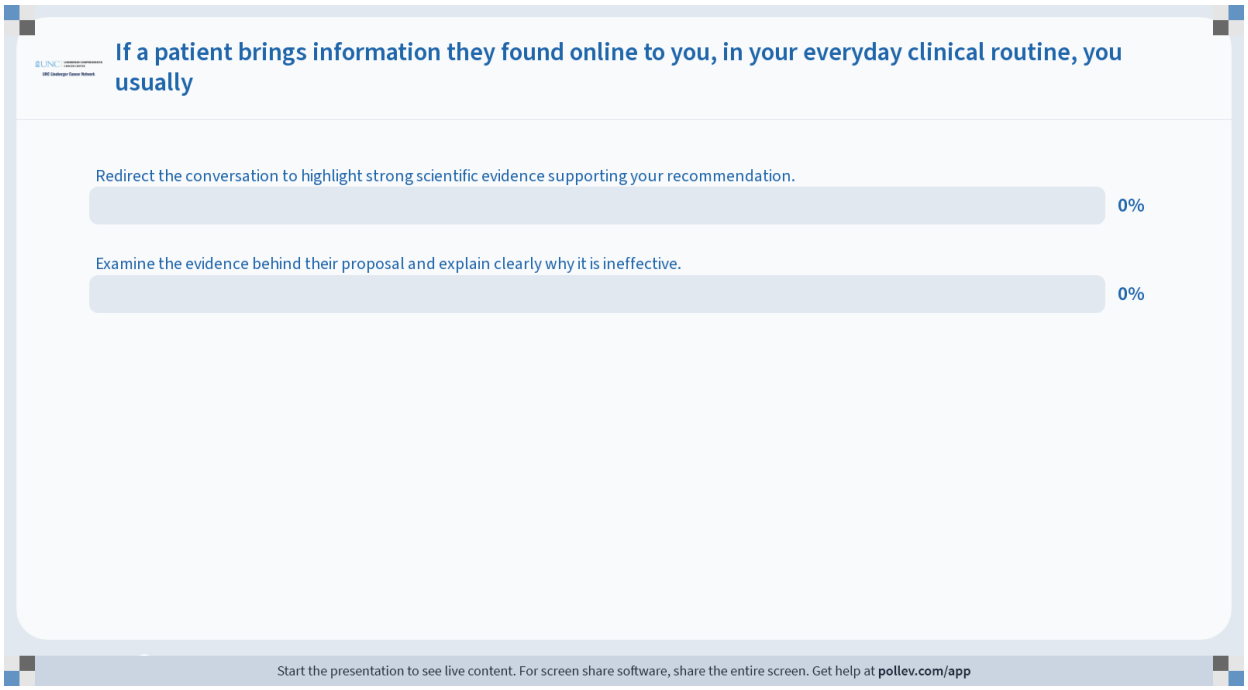

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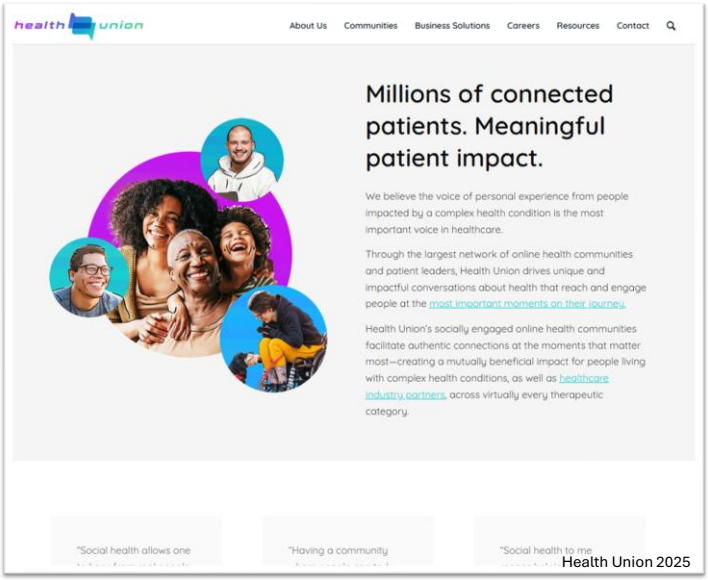
Population

N = 173
Age, years = 53
Sex, female = 45%
Race, White = 88%
Hispanic = 2%
Suburb or near large city = 49%
Health status, poor/fair = 54%
Cancer type:

- Breast = 26%
- Lung = 17%
- Prostate = 16%
- Colon or rectal = 9%
- Others = 32%



Health Union 2025

Fridman et al., 2025, JCO OP

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How do providers respond to such inquiries?

- We found: 31 - 37% of patients with cancer reported provider strategies that were **negatively** associated with:
  - trust in providers' opinions
  - future disclosure
  - decision self-efficacy

Ignoring: I often feel like I am being brushed off when I mention things I have learned

Discouraging: My husband looked into medical marijuana… We asked about an alternative. We were discouraged to look further.

Judging: I did research on the internet. My surgeon almost made it seem foolish that I would even look.

Missed Opportunity to Build Trust

Fridman et al., 2025, JCO OP

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If you need to disagree with patients, which approach will likely lead to a patient trusting the physician opinion?

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Experiment

...Imagine that you ...found a new treatment for your cancer online... You ask a healthcare provider about that treatment. Here is what happens:

Dismissal	Scientific explanation	Scientific explanation and relationship building
The doctor quietly looks at you while you are talking and then says that you should not believe everything on the Internet. The doctor turns the conversation to a different topic, which is related to the treatment supported by his/her clinic.	The doctor states that this treatment is not really going to do anything. The doctor explains that the information you have found about the treatment is likely incorrect. It is cancer misinformation. The doctor provides a detailed explanation of why the treatment is not going to work for you.	- The doctor listens, acknowledges, and confirms his/her understanding of the information. - [*Scientific explanation*] - The doctor says that regardless of what you decide, she/he will still take care of you and will always be available to answer your questions about these kinds of things.

Fridman et al., 2025, JCO OP

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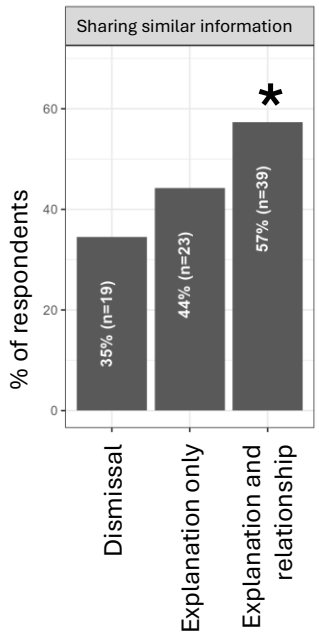
Results



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Fridman et al., 2025, JCO OP

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Conclusion

<u>Approaches that will increase patient trusting in physician opinion:</u>

- Taking patient information seriously
- Reassuring patients that they will be supported when they make their decision regardless of their choices

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What other research shows?

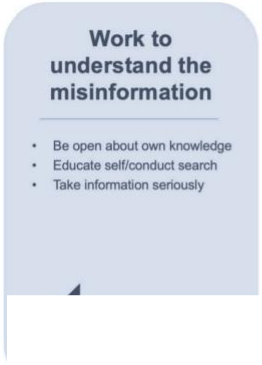

Fig. 3. Misinformation Response Model.

Mullis et al. 2024

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Takeaway Message

- Publicly available health information impacts knowledge and adherence to health recommendations
- Substantial proportion of patients search internet but hope to validate their decisions with an expert
- Medical professionals need to focus on building relationships via
  - Engaging with information patients find
  - Providing education
  - Identifying compromises and individualized solutions.

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Questions, suggestions, comments?

Topics Discussed	
What is misinformation	Misinformation should be defined with in each context
How patients decide to trust misinformation	Patients hope for supportive communications and information validation
How do disagree with information patients brought in?	Supportive communications: - acknowledgement of information - continuing support regardless of patients' decisions

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Questions/Comments?

Nobody has responded yet.

Hang tight! Responses are coming in.

Start the presentation to see live content. For screen share software, share the entire screen. Get help at **pollev.com/app**

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Thank you!

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Assistant Professor at Hackensack Meridian School of Medical School and Georgetown University Lombardi Cancer Center

Disclosure: Chat Bing 4.0 assisted with editing this presentation

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The song ***Back Rhodes*** written and performed by **Don Poe**

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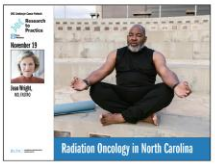
12:00 PM

Genitourinary Cancer Management in North Carolina
Catherine Fahey, MD, PhD

Patient-Centered Care

November 12
12:00 PM

Wayfinding: Moving from Risk Prediction to Action on Acute Care Events in Oncology
Jacob Stein, MD, MPH **Jennifer Lafata,** PhD



Research to Practice

November 19
12:00 PM

Radiation Oncology in North Carolina
Jean Wright, MD, FASTRO

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Jeffrey Aldrich, MD

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