“Palliative and Psychosocial Services for Cancer Patients” (James Tulsky) [#85]

Brad Power
February 7, 2024

“If an oncologist recommends a palliative care clinician, it's not that they're telling you you're going to die next week. They are saying that maybe this person can help in your quality of life.”
– James Tulsky

“As far as timing, all the data and all literature would suggest that earlier conversations are always good. It all depends on what you're talking about. A conversation in which you express what's most important to you, when your deepest held values are shared with somebody so they can be recorded, so they know what's going to drive your decision-making throughout. Also that we make sure that you have as clear an understanding as possible about the disease and where things are heading, what the possibilities are.” - James Tulsky

Meeting Summary

Advanced cancer patients experience many mental and physical symptoms from their disease, including pain, depression, anxiety, nausea, constipation, neuropathy, urinary problems, and sexual problems, and their families also experience distress. To relieve these symptoms and improve the quality of life for both the patient and the family, palliative care and psychosocial oncology provide medications, counseling, care coordination, relaxation techniques, and other forms of support.

Dr. James Tulsky, Poorvu Jaffe Chair, Department of Psychosocial Oncology and Palliative Care at Dana-Farber Cancer Institute, Chief, Division of Palliative Medicine, Brigham and Women’s Hospital, and Professor of Medicine at Harvard Medical School, is uniquely qualified to talk about palliative care and psychosocial services. He has a longstanding research interest in clinician-patient communication and quality of life in serious illness. He is a Founding Director of VitalTalk (www.vitaltalk.org), a non-profit devoted to nurturing healthier connections between clinicians and patients through communication skills teaching.

What are the issues that you may be facing that support services in large cancer research centers can address?

- Physical symptoms, such as pain, nausea, and fatigue
- Psychological symptoms, such as depression and anxiety

How can you access services to address these issues?

- You just need to ask.
- You may receive a “distress screening tool” – survey questions about your psychological or social symptoms, or social concerns – identifying if you are in need of help.

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- You can have a conversation with an oncology social worker to identify distress and other symptoms and who you need to see (such as psychologists, psychiatrists, palliative care doctors, and nurse practitioners).
- Your physician is trained to have “serious illness conversations” with you. The question for any given treatment is what matters most to you, about whether the benefits outweigh the burdens at that moment for that treatment for you.

What is some of the research that is being conducted in supportive care at Dana-Farber?

- Machine learning/AI in palliative care: trying to predict a patient’s symptoms before they occur, or know about them, even if they’re not expressed elsewhere
- Serious illness communication: which communication approaches are most likely to lead to the best outcomes
- Promoting resilience for patients, caregivers, clinicians
- Psychedelic-assisted therapies, e.g., psilocybin in hospice care
- Cannabinoids for cancer-related anxiety
- Cancer pain and substance use disorder
- Caregiving and stem cell transplant

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Meeting Notes

KEYWORDS

patients, palliative care, psilocybin, dana farber, call, cancer, care, work, pain, psychosocial oncology, oncologist, cancer patients, conversation, symptoms, cancer centers, clinicians, mentioned, oncology, treatment, issues

SPEAKERS

James Tulsky (69%), Brian McCloskey (12%), Jeff Krolick (10%), Amit Gattani (6%), Rick Stanton (3%), Jeff Waldron (1%)

OUTLINE

1. Introductions. (0:00)
2. Cancer care and supportive oncology. (2:25)
3. Patient-centered care and end-of-life decision-making at Dana Farber Cancer Institute. (7:43)
4. Cancer care, research, and communication. (12:34)
5. Cancer center's distress screening tool and eliciting accurate patient information. (18:04)
6. Palliative care for advanced cancer patients. (22:51)
7. Cancer treatment options and palliative care. (27:50)
8. Palliative care access and reimbursement for oncology patients. (33:30)
9. Psilocybin for palliative care and pain management. (39:12)

SUMMARY

- **Cancer care and supportive oncology.** 2:25
    - Dr. James Tulsky introduces himself and his department, Psychosocial Oncology and Palliative Care at Dana Farber Cancer Institute.
    - He provides an overview of his department's work, including their focus on supportive care in cancer treatment.
    - Psychosocial oncology addresses psychological, behavioral, emotional, and social issues for cancer patients and their loved ones, while palliative care focuses on relieving suffering from symptoms and the stress of living with cancer. It also helps patients match their treatment options to their goals.
    - Palliative care professionals, including social workers, pharmacists, and chaplains, work alongside oncologists to provide extra support and help patients live as well as possible with cancer.
- **Patient-centered care.** 7:43
    - Dr. Tulsky discusses Dana Farber's approach to supportive oncology, which involves identifying symptoms and distress in patients and caregivers, and collaborating with oncology social workers, psychiatrists, and palliative care physicians to provide effective care.
    - Dana Farber has started a program called supportive oncology teams, which brings together patients, caregivers, oncology social workers, psychiatrists, and

    - palliative care physicians to provide comprehensive care and address symptoms and distress in a collaborative manner.
    - Dana Farber and other cancer centers are part of a network working together to ensure patients receive care that reflects their preferences, particularly as their cancer advances.
    - The project aims to identify patients who would benefit from conversations about their goals of care, and enhance clinician skills in communication through evidence-based training.
- **Cancer care, research, and communication.** 12:34
    - Dana Farber is training nearly 300 oncology clinicians in communication skills and researching the "science of caring" to improve patient outcomes.
    - Dana Farber is using machine learning and AI in palliative care to predict patient symptoms, develop personalized treatment plans, and promote resilience.
    - Dr. Tulsky discusses the complex issue of managing cancer pain.
    - Brian McCloskey raises the issue of stoicism among cancer patients and the difficulty of addressing cognitive dysfunction and brain fog in men, as they may be less likely to seek help.
- **Cancer center's distress screening tool and eliciting accurate patient information.** 18:04
    - Cancer center screens for distress using validated surveys and assessments with social workers.
    - Dr. Tulsky mentions that caregivers can provide valuable insights into a patient's condition, and eliciting more accurate information from them can be helpful (0:21:30).
    - Amit Gattani wonders when the right time is to have the conversation with the patient, as having it too early or too late can impact the patient's experience (0:22:09).
- **Palliative care for advanced cancer patients.** 22:51
    - Palliative care clinicians help improve quality of life, not just focus on death.
    - Early conversations about end-of-life care can help avoid harm from delayed discussions.
- **Cancer treatment options and palliative care.** 27:50
    - Amit Gattani emphasizes the importance of considering a patient's quality of life and treatment burden when making decisions about cancer treatment.
    - Dr. Tulsky highlights the individualized nature of cancer care, where providers recommend treatments that align with a patient's unique values and priorities.
    - Brian McCloskey and Tom Smith discussed their experience with palliative care, with Brian mentioning their training in the program from 1995 to 1998.
    - Rick Stanton expressed interest in palliative care at UCLA and asked if it was available for wider group participation.
- **Palliative care access and reimbursement for oncology patients.** 33:30
    - Rick Stanton suggests asking oncologists about palliative care options, as they may not always be aware of available resources.
    - Oncologists may hold misconceptions about palliative care, and social workers can help triage needs for psychiatry or psychology.
    - Dr. Tulsky discusses challenges with reimbursement for psychosocial care in oncology, mentioning that Dana Farber loses money on social work services but is subsidized by the hospital.
    - Dr. Tulsky and Jeff Waldron discuss the value of improved outcomes and the potential for changing the equation through payment reform.
- **Psilocybin for palliative care and pain management.** 39:12

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  - Jeff Krolick discusses challenges with long-term androgen deprivation therapy and psilocybin trials for cancer patients.
  - Jeff Krolick highlights the benefits of psilocybin therapy for cognition and acceptance of death, citing personal experience and familiarity with advanced cancer patients.
  - Dr. Tulsky discusses the legal and therapeutic use of psilocybin, emphasizing its potential as an adjunct to psychotherapy and the need for more research on microdosing.
  - Dr. Tulsky discusses psilocybin-assisted therapy for opioid-resistant cancer pain, highlighting the complex nature of pain and the potential for existential exploration through psilocybin.
  - Brian McCloskey and Jeff Krolick discuss potential collaboration on writing a grant for cancer communication research.
  - Dr. Tulsky expresses support for patient involvement in research projects and mentions the expectation for some grants to have patient representatives working with the research team.

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TRANSCRIPT

Brian McCloskey
Welcome everybody to the Cancer Patient Lab. I am Brian McCloskey, a co-founder of the Cancer Patient Lab. We are excited to have Dr. James Tulsky here with us. He is the chair of the Department of Psychosocial Oncology and Palliative Care at Dana Farber. He is going to be talking to us about the physical symptoms that patients that are getting cancer treatments have to undergo, that affect us both physically as well as mentally. He is a world renowned expert on this.

We're honored to have you here. You have mostly patients on the call, some scientists, and others. Many of them are prostate cancer patients, but we also have brain cancer and pancreatic cancer represented. Those are the three cancer settings that we serve. I'm sure that what you're talking about really affects many cancer patients, so this will have wide applicability.

James Tulsky 2:25
Thank you very much. It's a pleasure to be here. What you guys are doing is really interesting, I had a conversation with Brad about it. Hopefully I can be helpful.

You mentioned three different cancers. I take care of patients in lots of different cancers, but certainly those three are absolutely included in the mix. Not just me, but our whole department.

I'm going to give you an overview of what we do, and where I'm coming from in terms of how we organize our care, what it is that we were stumbling through, the name of our department, and what everybody does. It probably is worth some definitions, which I'm going to give you, and then also a very broad overview of the kind of research projects that go on in our department, so you have some idea of the breadth of the kind of work that we do.

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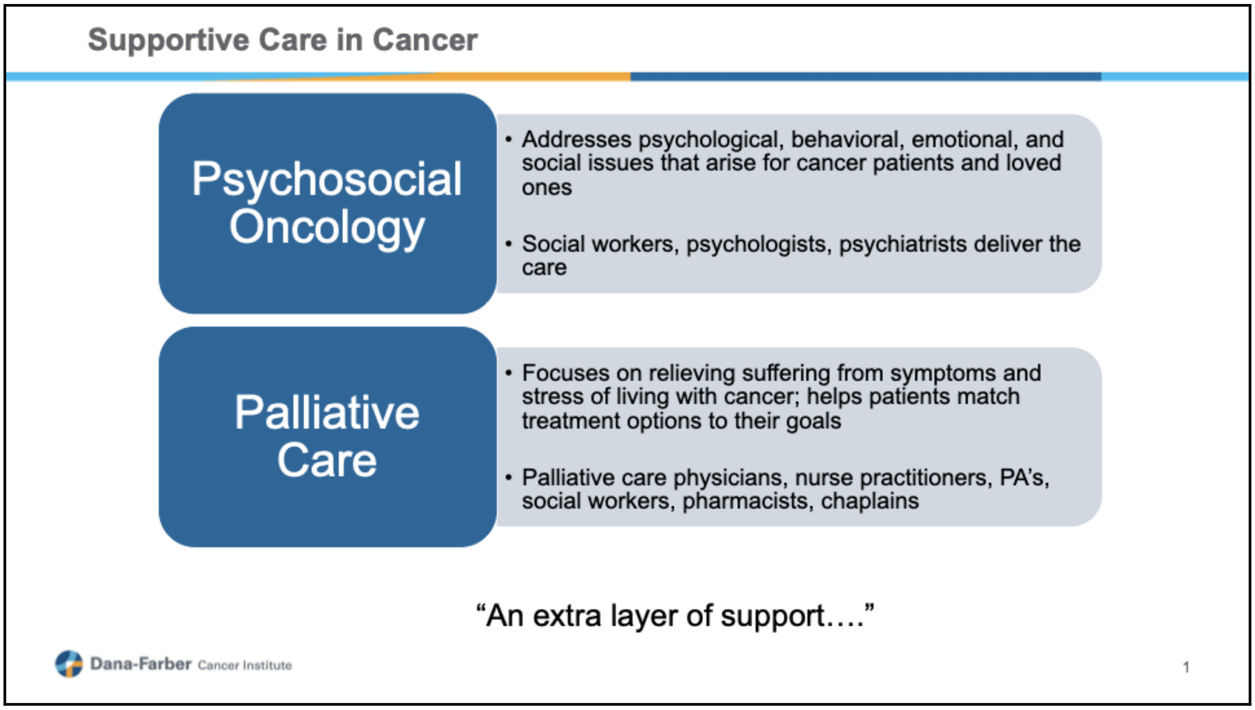

Supportive Care in Cancer

Psychosocial Oncology

- Addresses psychological, behavioral, emotional, and social issues that arise for cancer patients and loved ones
- Social workers, psychologists, psychiatrists deliver the care

Palliative Care

- Focuses on relieving suffering from symptoms and stress of living with cancer; helps patients match treatment options to their goals
- Palliative care physicians, nurse practitioners, PA’s, social workers, pharmacists, chaplains

“An extra layer of support….”

Dana-Farber Cancer Institute

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James Tulsky 3:55
I'm going to speak specifically about Dana Farber, but most of what I'm talking about is universal at most cancer centers, certainly the big cancer centers. Most of them have a department or division or some sort of grouping that does the kind of work that we do. They are not always organized the way that we're organized.

Our department is called psychosocial oncology and palliative care. That is a mouthful. If I would have renamed it, I would have called it the Department of Supportive Care or the Department of Supportive Oncology, which I think is an easier way to think about it. Supportive care in cancer, which is often one of the headings that this stuff goes under, includes a couple of things.

One of those is psychosocial oncology. This is essentially the field that addresses psychological, behavioral, emotional, and social issues that arise for cancer patients and their loved ones. We think a lot about caregivers as well as patients themselves.

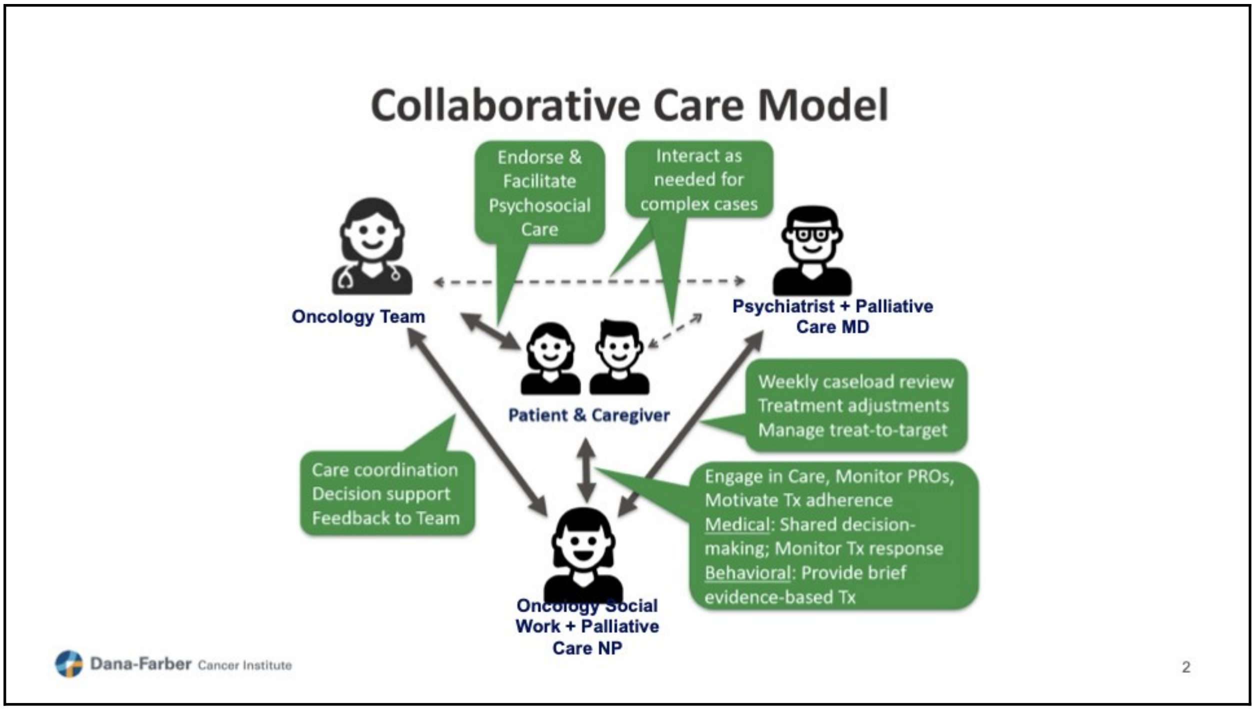
Who are the people that are doing this work? Social workers, psychologists and psychiatrists are the primary people that are doing this work, addressing a whole variety of symptoms, concerns, and issues that arise for people with the goal of really helping people cope as well as possible with their cancer.

Palliative care is adjacent, and has those agencies and is similar in certain ways, but is quite different in others. Palliative care focuses on relieving suffering from symptoms and the stress of living with cancer. It also helps patients match their treatment options to their goals. That's a big deal for us.

The people that do palliative care are palliative care physicians and nurse practitioners. We have PAs (physician assistants) as well as social workers. We have palliative-care-trained social workers, who are really different from more generic oncology social workers. We have palliative care pharmacists here. We work with chaplains as well.

As you can see, all the work that we do, whether you call it psychosocial oncology or palliative care, is highly interdisciplinary. This is a team sport. There are many different kinds of people that can contribute to helping patients in these domains. While it looks like there's a lot of overlap, what I would say is all the physical type symptoms: pain, nausea, and fatigue, whatever, all those fall much more under the palliative care realm. The psychological symptoms, like depression and anxiety, are more likely to fall in the psychosocial realm. That said, palliative care people do treat a lot of that as well. There are a lot of interventions that go both ways.

A term we often like to use is that we are “an extra layer of support”. We manage patients alongside their cancer care providers. What I often tell patients is that the oncologist's job is to treat the cancer, and my job is to treat everything else about you, and to help you live as well as possible with the cancer. That is not to say at all that the oncologists are not focused on that. They absolutely are. It's just that when things get tough, it's often helpful to bring another set of hands.



Collaborative Care Model

Endorse & Facilitate Psychosocial Care

Interact as needed for complex cases

Weekly caseload review
Treatment adjustments
Manage treat-to-target

Care coordination
Decision support
Feedback to Team

Engage in Care, Monitor PROs, Motivate Tx adherence
Medical: Shared decision-making; Monitor Tx response
Behavioral: Provide brief evidence-based Tx

I want to talk for a moment about a direction that we are heading here at Dana Farber. I want to believe that we're the leaders in this. I want to believe that others are going to move more in this direction.

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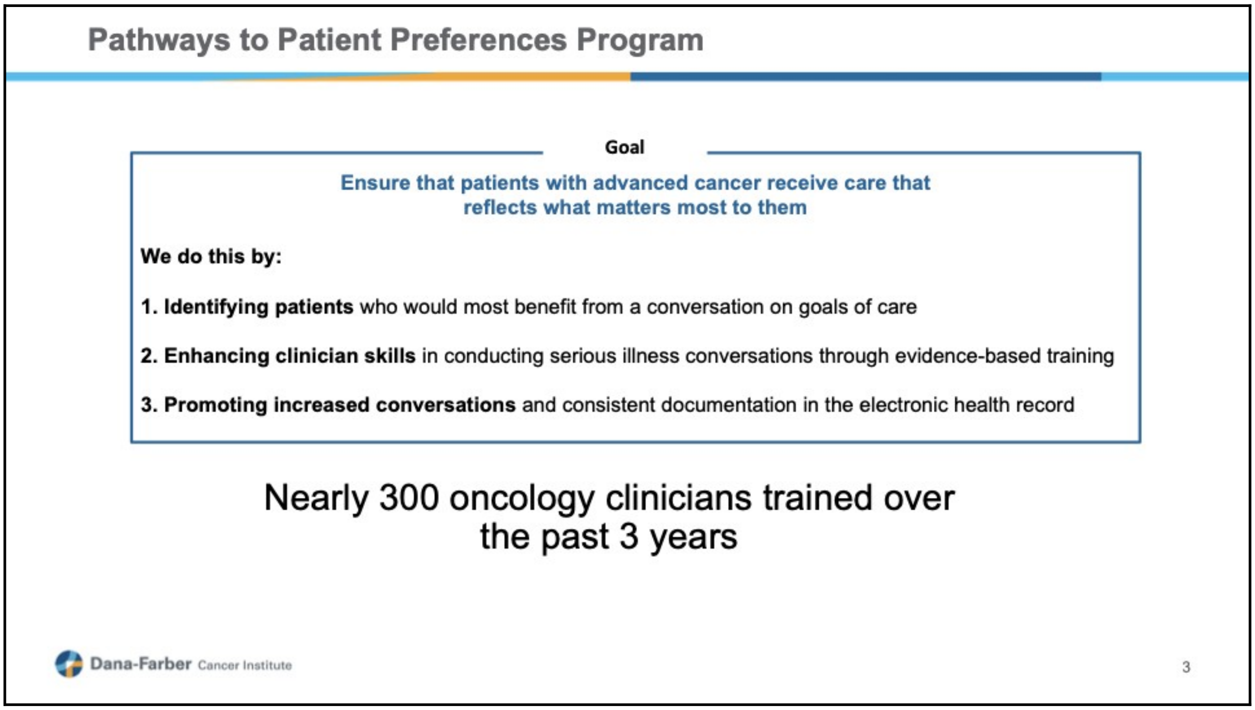
This is a collaborative care model, where we are trying to merge and bring together the psychosocial oncology and the palliative care work. We're doing this now in the Dana Farber network, which are our satellite centers. We have a number of them around Massachusetts and New Hampshire. We originally did this partly because we just couldn't get our psychiatrists and palliative care physicians out to those sites. It's too hard. But we could do this in a more collaborative care model and some remote care.

We're now adopting this model, which has been so effective in many ways, to what we're doing here at our major academic center. We're creating something called supportive oncology teams. The idea is that we're trying to identify symptoms upfront, identify distress upfront, and then figure out who needs to be seen.

The oncology social workers tend to be the captain of this, doing first assessments on people then figuring out who the patient needs to see, whether it's a palliative care physician or psychiatrist or whatever, then working collaboratively with the oncology team to make sure that we're able to be in communication as effectively as possible.



Pathways to Patient Preferences Program

Goal

Ensure that patients with advanced cancer receive care that reflects what matters most to them

We do this by:

1. **Identifying patients** who would most benefit from a conversation on goals of care
2. **Enhancing clinician skills** in conducting serious illness conversations through evidence-based training
3. **Promoting increased conversations** and consistent documentation in the electronic health record

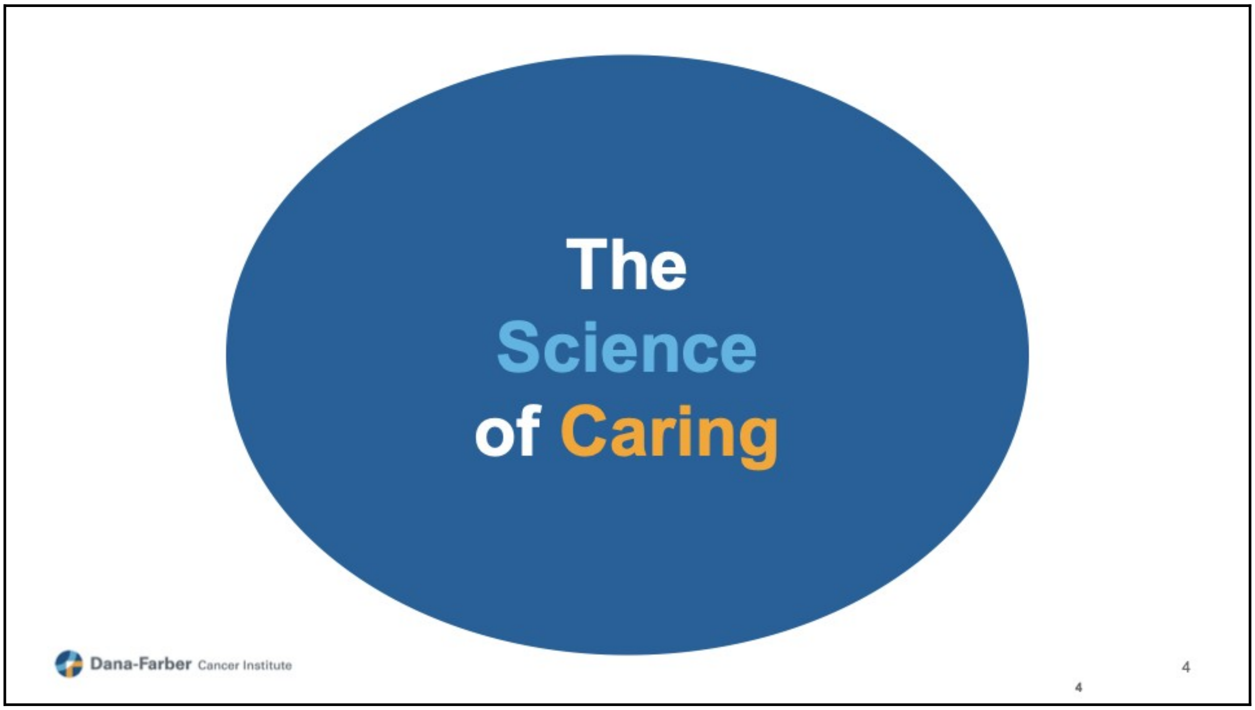
Nearly 300 oncology clinicians trained over the past 3 years

Dana-Farber Cancer Institute

I want to mention this program that has been going on for the last several years at Dana Farber called “Pathways to Patient Preferences”. This program is being done here. And we're part of a network of what's called “The Alliance of Dedicated Cancer Centers”, which is 10 or 11 of the premier named cancer centers. It's us, Memorial Sloan Kettering, MD Anderson, Fred Hutch, Moffitt, and others. We're all working in a collaborative to get this done. The goal is to ensure that patients with advanced cancer receive care that reflects what matters most to them. That, particularly as you get further along in your cancer, there are a lot of treatment decisions that are balances between quality of life, quantity of life, and so forth. Figuring out the best way to get there is not like an obvious oncologist recommendation. It really depends on what's important to the patient, and figuring that out. That requires a lot of good communication and being able to find out what's most important to people, and to make sure that you are communicating as much as possible about things like prognosis, and so forth.

Our project here is:

1. Identifying patients who would most benefit from a conversation about “goals of care”. I believe these conversations ought to happen for every cancer patient, but given limited time and resources, there are probably some patients who could benefit more.
2. A really key piece is enhancing our clinician skills and conducting “serious illness conversations” through evidence-based training. We use a program called “Vital Talk”. Many of the other cancer centers are as well. I founded this program. It's an international program that trains clinicians in communication skills.
3. Then we are promoting increased conversations and consistent documentation in the electronic health record because there needs to be a single source of truth for this so that if a patient has had a really good conversation in clinic with his or her team, and has expressed certain kinds of preferences that are really important to them, if they show up in the emergency room at 2:00 in the morning, we need to have a place to go and be able to know that. That's what we're doing. We have trained nearly 300 oncology clinicians here at Dana Farber over the past three years in full day communication skills training courses. And similar work is being done at the other centers, as I mentioned.



The Science of Caring

Dana-Farber Cancer Institute

I'm going to close with just a little bit about the science and the research. We've dubbed it here “The Science of Caring.”

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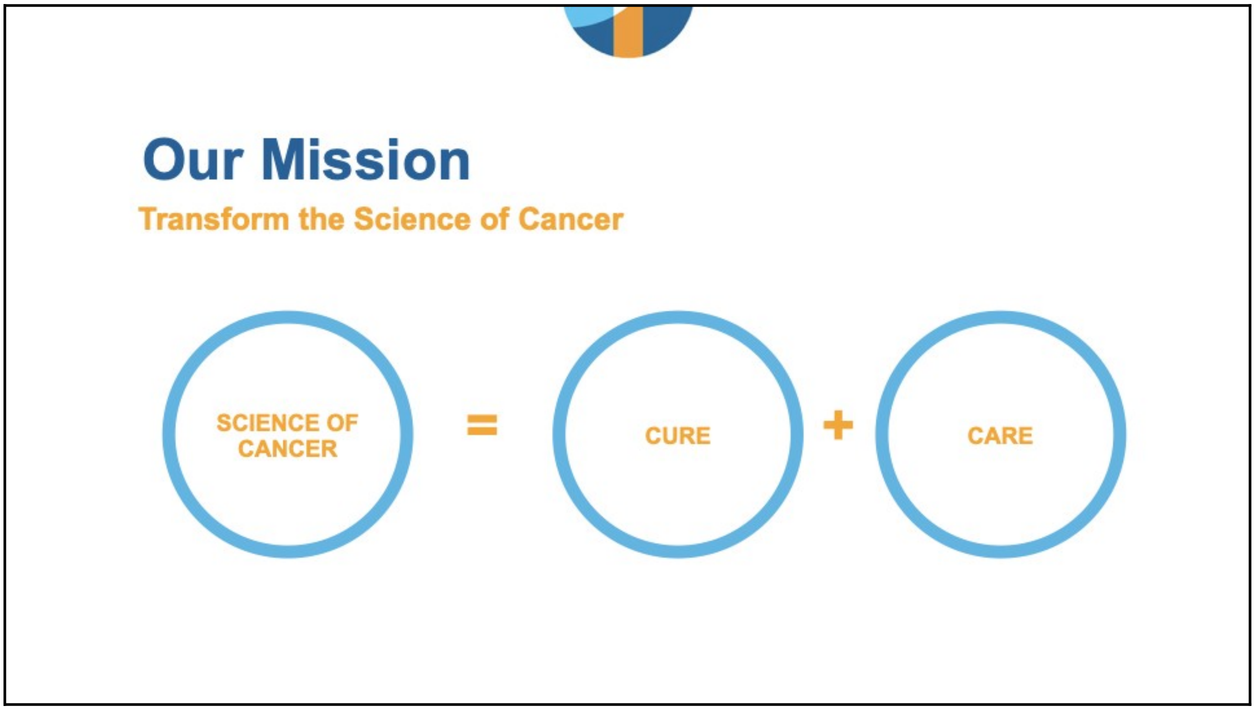
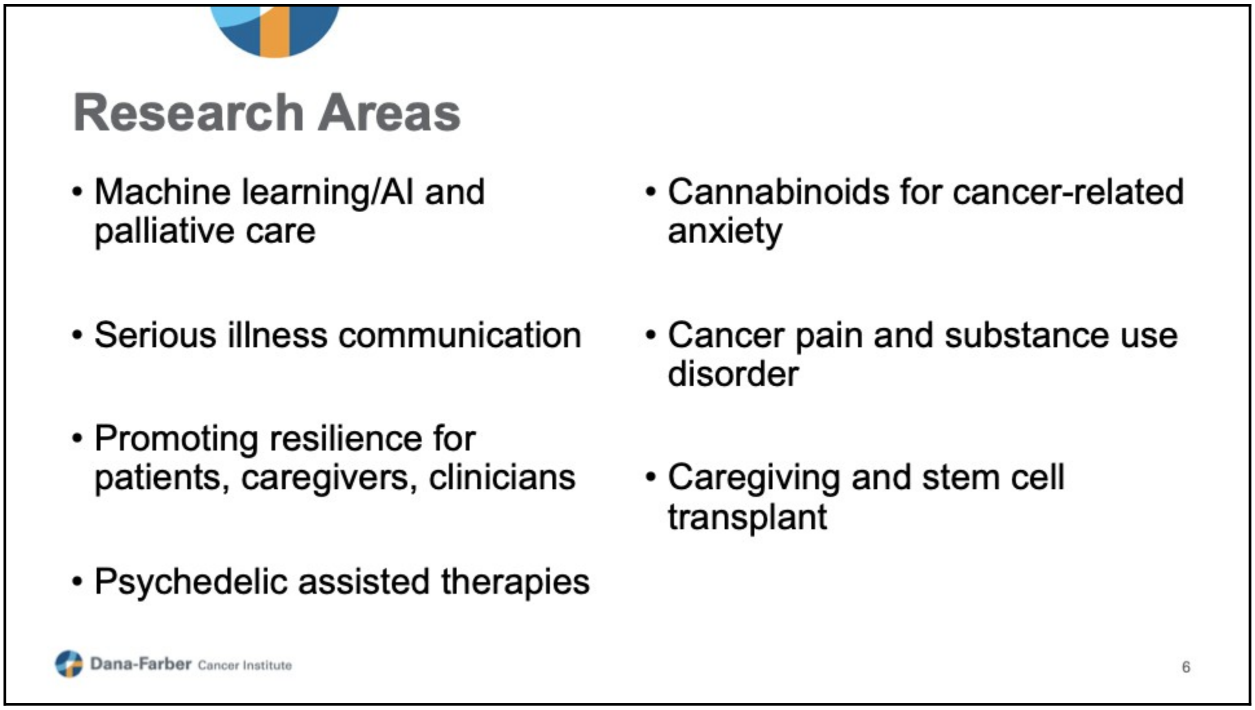


Our Mission

Transform the Science of Cancer

SCIENCE OF CANCER = CURE + CARE

Our idea is that the mission of Dana Farber is to transform the science of cancer. They often talk about the science of cancer. But if you think about what it is, it's really two different sciences in our minds. It's the science of cure, which is all the basic and translational science about how we come up with the best treatments possible for cancer, but it's also the science of care, which is how we create the best evidence around symptom management, around communication, and around other things that have a significant impact on the lives of patients living with cancer.



Research Areas

- Machine learning/AI and palliative care
- Serious illness communication
- Promoting resilience for patients, caregivers, clinicians
- Psychedelic assisted therapies
- Cannabinoids for cancer-related anxiety
- Cancer pain and substance use disorder
- Caregiving and stem cell transplant

Dana-Farber Cancer Institute

James Tulsky 13:37
This is my last slide. I'm going to quickly show you a whole bunch of things we're doing in research, mostly just to pique your interest, and then perhaps some people will ask questions.

We are doing a bunch of work using machine learning and AI in palliative care, to do things like try to predict a patient's symptoms before they occur, or to know about them, even if they're not being expressed elsewhere. Also new things like predictive analytics about which patients are going to benefit from certain kinds of treatments.

We do a lot of work here on serious illness communication. I already mentioned that. We've done a lot of different research projects, basically trying to hone down on what are the most effective ways to communicate with patients, tools, tricks, roadmaps, and which kinds of communication are most likely to lead to the best outcomes.

We have one major investigator here who does a lot of work on promoting resilience for patients, caregivers, and clinicians, and has developed an intervention called “PRISM”, which is used a lot all over. We are incorporating this here as well. It helps people figure out resilience.

We have a growing and exciting program in psychedelic-assisted therapies. We are running two trials right now. We have just completed one on psychedelic-assisted therapies in hospice care. It's a psilocybin trial. Another one is using psilocybin-assisted therapy for cancer pain, which we're about to launch.

Going along this theme of previously underground chemicals, we also have an investigator working in cannabinoids for cancer-related anxiety and other aspects of where cannabinoids may be helpful as well. That's the main indication we're looking at.

We have work going on in cancer pain and substance use disorder. One of the issues is that many patients have cancer pain. We prescribe lots and lots of opioids for this cancer pain, and it is very effective for lots of people. At the same time, we can't ignore an opioid misuse crisis going on in this country and patients. It is the rare but occasional patient who through the prescription of opioids can run into misuse problems. More commonly, we have patients who have a previous history of misuse. But now if they have pain, how do you manage that? There's a lot of issues there.

We do a lot of work in caregiving. We have one investigator primarily looking at caregiving in stem cell transplant. But we've also looked at caregiving in other settings.

Brian McCloskey 16:56
Thanks so much for this high level overview on a very complex topic that affects every patient on this call. One of the things that strikes me. I just got off a call with Bayer. They were talking about cognitive dysfunction related to ADT (androgen deprivation therapy), brain fog, and what to do about it. One of the challenges for men in general related to this topic broadly, is that we tend to be very stoic as cancer patients. When you're talking a little bit about identifying patients who would be most appropriate to treat because you're resource constrained, and all hospitals are resource constrained, how do you go about doing that? Because, frankly, every cancer patient needs this, as you said. It may be very difficult to assess in men because we tend to not address these issues.

James Tulsky 18:03
We have several different ways that we do this. The most common way we screen is a distress screening tool, which is survey questions. Everybody who walks in the door of our cancer center after their second or third visit, because a lot of people come for just consultations, and then don't come back, for the people that are going to be establishing care with us, all get a survey. They get these over time. We call it the distress screening tool. Basically, it's a bunch of questions about your symptoms. Many of these are psychological or social symptoms, or social concerns. These are validated instruments of abusive men, women, different cultures, all those kinds of things, that have a high sensitivity for picking up these kinds of concerns. Obviously, people can mitigate them when they respond to the survey. But people do respond. Anybody who scores above whatever the cutoff is, they then have an assessment with a social worker that sits down and talks to them and tries to uncover more of what's going on, see if they can be helpful in various ways, and then figure out if there are any referrals they need, or when there's any sort of interventions to be using directly. That's the way we screen for everybody.

Obviously, we get a lot of people just referred.

Yes, men are stoic, more so perhaps than women. Men also do share. At some point it usually comes out; whether it comes out in distress screening, whether it comes out from a caregiver or a spouse or family member, it's not infrequent that we will get a phone call or even in the visit. I can't tell you how many times I have a visit, whoever comes into the visit with the patient starts telling me, “Well, he's not really saying X, Y, and Z, and this is really what's going on.” We hear that. It's up to the patient to decide whether they want to accept any of the interventions we might offer. Many people refuse to see the social worker and refuse to enter into some other kind of treatment modality. It's then our job to be as motivating as possible to learn as much as possible, and to move forward. It is hopefully within our skill set of all the various care providers I mentioned, to be able to elicit concerns from patients and be able to find out more than the average person on the street might find out. So that's how it happens.

Brian McCloskey 21:29
It's an interesting topic. I'm glad that you mentioned the caregiver because I know that my wife would say, “What he just described in terms of his symptoms, and how he's behaving, is simply inadequate or inaccurate.” She'll give the real deal. A focus on caregivers might be really, really helpful in eliciting more accurate information about the patient where possible.

Amit Gattani 22:09
In your research topics that you listed, I’m wondering if you also look at when is the right time to have this conversation with the patient? Because if you have the conversation too early, you're indicating to the patient that not much is left, and they should just take this path. And if you have it too late, then maybe you haven't supported the patient.

As my own example: I'm an advanced prostate cancer patient. My oncology team has been talking about palliative care for maybe 15 to 18 months. I have a palliative care doctor on my panel. We just keep finding a way of pushing the boundaries of something. It almost bugs me, the fact that you are no longer even saying, “Hey, you should consider palliative care.” 18 months back. That's just very discouraging. It can be a very discouraging thing for patients.

James Tulsky 23:36
Thank you for the question, because it allows me to start by shattering a myth about palliative care. We are not about death and dying. We are not about killing people off, or helping them in that way at all. We celebrate cancer treatment successes, as much as the oncologists do. Palliative care is an adjunct to treatment-directed cancer care that allows focusing on quality of life and relief of symptoms and an understanding of disease that's alongside your cancer. I have patients I have followed as a palliative care clinician for six or seven years. That's just because I've been at Dana Farber for eight years. There's no boundary on that. I hope if you leave here with anything it’s that if an oncologist recommends a palliative care clinician, it's not that they're telling you you're going to die next week. It's that they are saying maybe this person can help in your quality of life.

There was a very important randomized controlled trial that was published in the New England Journal of Medicine in 2010 that compared early palliative care for patients with metastatic lung cancer versus usual care, meaning no palliative care unless the oncologist asked for it. Not only was quality of life higher in the group that received the early palliative care and actually lived three months longer. There are a whole bunch of reasons why that probably was the case. It’s just an important thing for people to recognize.

It’s a separate conversation about when is the right time to stop cancer-directed therapies. The overwhelming majority, in fact, almost all of my patients right now are receiving cancer-directed therapy. Some of them at some point may choose to stop. Or there may simply be nothing that oncologists are willing to offer. Although around here, that's unusual.

As far as timing, all the data and all literature would suggest that earlier conversations are always good. It all depends on what you're talking about. A conversation in which you express what's most important to you, when your deepest held values are shared with somebody so they can be recorded, so they know what's going to drive your decision-making throughout. Also that we make sure that the patient has as clear an understanding as possible about the disease and where things are heading, what the possibilities are. That conversation can always be had early. The data would suggest that earlier is better. I can tell you that in my own experience, it's rare for any patient that I can think of where they've been harmed by good discussions early on. They can be harmed, perhaps, by bad discussions. I won't take that away. That's why it's really important for oncologists, healthcare clinicians, and others to have the skill to have the conversation well, but I have seen lots and lots of harm from conversation started too late. If I had to bias in one direction, I think that's pretty clear to me.

Amit Gattani 27:37
I get your point. Maybe I didn't phrase my narrative properly. It wasn't just about palliative care, it's about where you are in the treatment. Is it better to stop the treatments in our type of situation? I find that, whether it's a legal liability issue, or whatever it is. When you have that conversation on prognosis and data, doctors tend to be conservative because they can only rely on what they can rely on, which is published data, which may be fairly old at some point. It's not based on new innovative therapies that may be becoming available. You're given a prognosis, which is always on the very conservative side, and hence you may get directed to whether it is time to stop the treatment and consider balancing the quality of life and the treatment.

James Tulsky 28:53
First of all, no one should ever be giving a specific prognosis. That's absolute. Everyone's on a range. Certainly, that's the way we teach it. That's the way I hope people mostly do it. All you can do is express a probability. Then the question for any given treatment is really about whether the benefits outweigh the burdens at that moment for that treatment, and in light of what's important to that patient. The burden is where everybody's different. In the three minutes we are getting to know each other here, I have a good sense of where you put that balance, and what I would probably recommend. For example, I may find myself recommending to you a far more aggressive approach than I would recommend to somebody else who clearly has a very different threshold for what they are willing to endure for possible outcomes. That's the whole thing. It's not that there's any one right way to go. It's our job, as cancer care providers, to

recommend treatments that match what matters most to you. If you're the kind of person that wants to always be looking for that clinical trial anywhere in the world, we'll help you do it. And if you're the kind of person that has a different approach, and there are people that do, then they'll do that too.

Brian McCloskey 30:47
I wanted to point out that we had Dr. Tom Smith from Johns Hopkins here.

James Tulsky 30:55
I know Tom well. We go way back.

Brian McCloskey 30:56
I figured you did. He talked so much about the work that he was doing to bring palliative care into the conversation right from the get go with the patient. It's very consistent with your message here.

James Tulsky 30:58
Tom's an oncologist.

Brian McCloskey 31:15
I know. And he's a prostate cancer survivor. A lot of overlap there.

James Tulsky 31:33
[Shared a photo of a group with Tom Smith.]
We were all in something together. It has an awful name, which we have run far away from, but back in the 1990s George Soros funded something called “The Project on Death in America.” Like I said, terrible name. But he was trying to improve the dying experience for patients. He funded a whole program that trained cohorts of people over many years. Tom and I were in the first cohort in that program from 1995 to 1998.

Rick Stanton 32:18
I get care at UCLA, and UC San Diego a little bit, but mostly at UCLA. I've never been offered any palliative care. You mentioned that the big guys, the Moffits, the MD Andersons, I don't know whether UCLA is a big guy, but I'm interested, and I'm ready. I struggle with my attitude. Every day I pray to get my attitude straight, and who's the man that's going to walk out that door into the family room? And psilocybin, just whatever makes sense. But I'm certainly open.

Does UCLA and then opening it up for the wider group here, there's probably guys here that are interested in: is this palliative care available to me? And how do I find out about accessing it?

James Tulsky 33:36
UCLA definitely has a palliative care program. I know the folks there. They also certainly must have people doing psychosocial oncology as well. I know other people in LA do that. There is

definitely a very strong program and both those things at City of Hope, and also at Cedar Sinai, but UCLA does have a program, and it's an excellent cancer center.

We're not there yet. but we're trying to create a system that removes the oncologist referral piece of it, that just identifies people for what their needs are and then offers the things that might meet their needs. The problem is, if you do a referral, either because of conscious or unconscious bias, or because people just don't think about it or whatever, they may not make those referrals. The most common referral that we get, quite honestly, is for pain. I would probably say 75 to 80 percent of our palliative care referrals are for pain. We get more of the referral social work for just other things. The social workers will triage if you might need to see a psychiatrist or psychologist.

My advice is simply to ask. You just have to ask if it exists. Oftentimes people say, “Oh, I just didn't think about that.”

Oncologists hold some of the same misconceptions that I was railing against earlier about what “palliative care” means. I hope you don't hear this very much. You'll still rarely hear oncologists say something like, “You're not ready for palliative care.” I've just hopefully suggested that we're always ready, if we can be helpful, to address symptoms. The other thing is, depending on issues, like if it's about mood and stuff, palliative care may not be the first direction, it may actually be social work, psychology, or psychiatry. So that would be my recommendation: just ask. More and more centers now are certainly having it.

Jeff Waldron 36:23
I'd like to connect with you afterwards for a different reason.

Do you have challenges getting reimbursement for payers for providing psychosocial care for oncology patients?

James Tulsky 36:38
The answer is, “Not really.”

I know you said psychosocial. Palliative care is just reimbursed like a regular physician visit. I bill. I know Dana Farber gets paid. That happens. That's the same thing as for psychiatry, the same thing as for psychology. We don't bill for our social work visits. There are places that do. Our Director of Social Work used to be the Director of Social Work at City of Hope, but we recruited her here, and they at City of Hope do bill for social work care, we don't here. But it's possible to do that, as well.

Sometimes what happens is – not diving too deep into payment stuff – when you go to most comprehensive cancer centers, you're being charged a facility fee, in addition to a professional fee. Now, a facility fee is for everything, and that's what actually ends up paying for our social work, because they're bundled into that.

The simple answer is we do get paid for this. That said, Dana Farber loses money on us. We get paid, but we don't get paid what we actually cost. We are subsidized by Dana Farber. I'll name it: about $10 million a year. Which I am grateful for. When I walk into the office of Laurie Glimcher, the CEO, my boss, she'll look at me and say, “You're running a deficit. And, yes, we have to do this, because it's the right thing.” It's the care that we have to give. The way that we look at it, and the way most cancer centers should look at it, is that we are like a call center, like in any business. We're not the ones that make money. What makes money is pharmacy and oncology. They're going to make money there. But they need us to help do everything else.

Jeff Waldron 38:49
The more the payers understand the value you described a few minutes ago about improved outcomes could be a way to change the equation a little bit.

James Tulsky 39:03
We've been working on that. We make that case all the time.

Jeff Krolick 39:12
As you mentioned right at the beginning of your talk, we stumble over semantics. “Palliative care” for many of us has had a very particular association, which is to make somebody comfortable until they die, rather than supportive care for whatever else is going on. That's an important distinction. The billing is for “palliative care”, and that’s the terminology that's used, but that's an important step to take when discussing other services that are available.

I come from a behavioral health background, and we have a history of using people who've had the lived experience of mental illness for peer support. That's very, very effective. I don't know how that works with cancer patients. I use and benefit from the Cancer Patient Lab in exactly that way. It's a mix of doctors, mostly advanced cancer patients, but it's been very valuable for me, in my experience.

I've mentioned this before: Brian brought up the issue of cognitive challenges for many of us who are on long term androgen deprivation therapy, or even chemotherapy. That's a significant issue. I'm always impressed with many of the people in this group who are doing continuous androgen deprivation therapy because I know I feel it a little bit. I do intermittent androgen therapy, and I still can feel the effect of that.

One of the things you had mentioned is that you have some psilocybin trials going on. Now, I've been microdosing with psilocybin following a particular protocol, and I find it very beneficial for me. Although it's not a mood enhancer, it does improve my mood. It helps me see things more clearly. It brings more joy in. It helps with cognition substantially in many different ways. I'm certainly a proponent of that. It's quite different from psilocybin therapy with a large dose of psilocybin.

I wanted to highlight those couple of things. My partner is a clinical palliative care social worker for Kaiser, so I'm pretty familiar with palliative care. Many of her patients, if not all, are advanced cancer patients. I'm familiar with some of the challenges with that, and the challenges for people to accept not necessarily the end of life, but just the notion of death in their care and in their diagnosis.

James Tulsky 42:57
A really quick comment about psilocybin. By the way, as I think everyone knows, I’m not calling anything out here, but the only way it's actually legally available almost everywhere is through research. There are some other agents, like ketamine, which are legally prescribable. The way we're studying it is as an adjunct to psychotherapy. The classic sort of psilocybin-assisted therapy is exactly that. It's not psilocybin by itself. The idea is that psilocybin when used in larger doses, not microdosing, creates a neuroplasticity of the brain that allows people to think differently, and then the therapy itself allows you to actually reorganize that in ways that may be helpful going forward in the future. All the data that I'm aware of in psilocybin is about that. I don't think there's at least randomized controlled trial data or anything that's different about microdosing. I know that it's being done out there very actively. The one thing I'm just going to throw out is everything you say makes sense. Because what psilocybin does, is it's essentially a serotonergic agent. It's really not so different from taking an SSRI (Selective Serotonin Reuptake Inhibitor, a widely used type of antidepressant), if you do take it in microdosing, is my guess. But we don't really have any data on that. It’s an interesting question. Since so many people are microdosing, we ought to be doing studies on that. Although I'm not sure if the approach we're taking is more about the combined therapy.

Jeff Krolick 44:48
You mentioned the application of psilocybin for pain management. I'm wondering if you could say a little bit more about that.

James Tulsky 44:59
In the palliative care world, we talk about the concept of “total pain”. Pain is rarely just physiologic. There are neurological reasons, either because of somatic damage, leading to a pain impulse being brought to the brain or a damaged nerve, that's neuropathic pain, leading to a pain sensation. Those are purely physiologic. But total pain is a concept that was coined a long time ago by one of the founders of palliative care named Cicely Saunders in the UK, which is that pain is physical, psychological, social, and existential. All of those things contribute because pain is perceptive. It's not just the physiologic thing that's going on, but it's actually how you live, it's a reason why some people have high tolerance, some people have low tolerance, why pain can come in. It's just a very complex phenomenon, particularly when people have opioid-unresponsive pain, that we just can't get any management of, almost always there's a lot more going on there behind that pain. Our study is specifically for opioid refractory cancer. The idea is, if there are these other things going on, maybe through the psilocybin-assisted therapy, you can explore particularly the existential issues, which are the ones that are hardest to get at in other ways, and existential concerns.

Brian McCloskey 46:51

Is there any way that we can help you? One quick thought I have is potentially collaborating with you on writing a grant that might fit into your research? You have a patient-led organization that is very engaged.

Jeff Krolick 47:16
There are NIH grants available in a variety of approaches to studying cancer communication and the new information ecosystem. We're potentially interested in that. By ourselves, we're way over our heads with anything like that. But we're a pretty robust group and partnering with a larger organization that already has that interest and sophistication on this kind of grant. We would be very interested in it. I'm just going to put the specifics out. You may know this, and you may already be working on it.

Brian McCloskey 48:05
We can take this offline because I know that's a specific grant.

Any closing thoughts?

James Tulsky 48:17
It's great that you're doing what you're doing. You're absolutely right, we are often doing research projects, and we want to have patients involved. I first started using patient panels in projects a long time ago, about 10 or 12 years ago. Maybe I shouldn't have waited that long. Having that contribution makes a big difference in the quality of our work. It also honestly makes it more fundable. There's an expectation for some grants that you have to have patient representatives working with you. For others, it's optional, but it always helps the quality of the science. It's very useful for me to know that you exist out there, and we're going to turn to you when we are looking for partners for this sort of thing. I'm a big fan of patient advocacy and working on this.

Brian McCloskey 49:24
We can only cover a vast array of topics with just a very thin coverage of it, which is probably an opportunity to do some additional calls. We can dive in and follow up with you offline on that, as well as with the grant that Jeff is helping us to spearhead as he's had some experience with that. We'd love to entertain those opportunities.