Science AMA Series: I’m Dr. Arif Kamal, a palliative care physician at Duke University. Palliative care clinicians across the world take care of patients with incurable illnesses, including those with

DR_ARIF_KAMAL R/SCIENCE

ABSTRACT

Hi r/Science! My name is Dr. Arif Kamal and I am a palliative care physician at Duke University. Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

As a palliative care physician, I hope to demystify what palliative care means to those who worry that a focus on quality of life during incurable illness may mean shortening life in the process, or even worse, that we have anything to do with “death panels”.

In addition to direct patient care, I also co-founded the Global Palliative Care Quality Alliance, a collaboration of palliative care organizations dedicated to exploring how to further best practices and quality within the palliative care field. On October 15th, we will be holding the first virtual conference dedicated to quality within palliative care called the Quality Matters Conference. To find out more about the GPCQA and the Quality Matters Conference, visit us at www.gpcqa.org.

I will be answering your questions at 4 pm ET (1 pm PT, 9 pm UTC). Ask Me Anything!

Don’t forget to follow me on Twitter @arifkamalmd and the Global Palliative Care Quality Alliance @GPCQA

How can hospitals transition from largely using palliative care physicians for pain management after treatment, to having them become part of the discussion of treatment options?

KindtoEveryone

In my experience, most palliative care programs in hospitals spend most of their consults with patients either doing focused symptom management (e.g. pain refractory to usual medications) or counseling near the end of life. As palliative care is better understood, upstream involvement is doing exactly what you ask, including the team as part of making decisions regarding continuing or stopping disease-directed treatment. The field is getting there.

I have a question in regard to the palliative environment. How much does the design of rooms and wards in which the patients live and die, come into play as far as psychologically easing stress?

pas46
This is a really great question, and something of which I unfortunately don't have a huge knowledge base. In most countries, people have a strong preference for dying at home, so I would imagine anything that can be done to make the environment in which patients die as home-like as possible would be beneficial. This goes above and beyond simply the interior design of the room itself, but could also include elements of home such as non-restrictive visitor hours so families can be more present or a higher quality of food for patients.

You describe an ideal case scenario of palliative care in which an appropriately trained team of specialists is indeed available to provide care. Sadly, it is often the case in resource-limited settings that the burden of palliative care is shouldered solely by untrained family members who learn by trial and error, a process during which the patient's quality of life is far from what could be optimally achieved. Has your group attempted to provide learning materials at a layman level which would help such impromptu caretakers have an easier transition into an acceptable level of proficiency?

Full disclosure, I am currently working in a pilot study in which we intend to reach these informal caretakers and hand them tablets equipped with video tutorials and other features in order to (hopefully) address the issue outlined above.

joevector
Sounds like an interesting project. There are some projects right now that focus on the informal caregivers. For example, the work by Bakitas et al. at the University of Alabama - Birmingham actually focuses on developing materials and programs to address the caregivers in a telephone-based intervention. Further, Ferrell et. al. at City of Hope recently reported a lung cancer intervention that also developed training materials for informal caregivers.

Ok, I'll bite... Why do people mistakenly "worry that a focus on quality of life during incurable illness may mean shortening life in the process"?

Are people so afraid of the (nonexistence of the) afterlife that they would rather suffer, or worse, make someone else suffer, in life?

Jobediah
They misunderstand that a conversation regarding patient wishes and their "ideal future" means anything other than honoring the patient. Certainly, if palliative care had an "agenda", like what many people incorrectly assert (e.g. trying to save hospitals money, working for the payers), then the worry would have merit. But palliative care actually asks patients, "What's important to you?", and it ends up being that chemotherapy 2 weeks before dying is just not that important to most people.

How is palliative care different from hospice care? What are the major differences?

kit10 butt
The other replies here have done a great job of addressing this question. Much in the way that all squares are rectangles but not all rectangles are squares, all hospice care is palliative care, but not all palliative care is hospice care. Palliative care is any care that focuses on quality of life and symptom management. Hospice care is a certain type of palliative care given when patients have a prognosis of less than six months.

u/DeepSeaDweller raised an interesting point that palliative care is not always solely for patients with incurable illness. In fact, something as simple as taking Tylenol when you have a headache could be considered palliative care. However, in the field of palliative care in the current medical setting, most referrals that I receive are patients with incurable illness.
What is your position on assisted suicides for patients who are, one, dying and in terrible pain, and two, are just miserable but will live a long life in a that state?

donotbelieveit
I personally think that for the vast majority of patients (and certainly all the patients I've seen), timely and intensive palliative care, either in the form of consultative palliative care or hospice, can avoid needing to feel like assisted suicide would be needed. Generally speaking, most palliative care clinicians feel this way as well, although the decision to participate in this is very individual to physicians.

Hi Doctor. First of all, thank you for the work that you do. Here's my question. I'm a smoker and I want to quit. Have tried many times before and been unsuccessful. You read these articles about how smoking just one cigarette can cause cancer to form in the human body, or that even 30 years later you can die from smoking related cancer even if you quit 30 years ago. It's taking away my motivation to quit because I think - 'well, I've been smoking for 15 years, I'm probably going to die from it anyway.' As in, I stop smoking but the damage I've done will catch up with me anyway. If I'm going to die from smoking, why not smoke (which is pleasurable) anyway? What are your thoughts? I still want to quit. Thank you.

marmletea
First off, as you said, quitting is hard. But it is extremely important, no matter when you do it. For example, we believe that the increased risk of cancer from smoking largely is not a factor in cancer development as early as 15 years after a person quits. Put in another way, we do not consider smoking a driving factor in cancer development if people have quit more than a decade prior. Further, we know that smoking during cancer treatment increases the risk of bad outcomes, so even after cancer forms, smoking cessation is important. Good luck to you.

Could you discuss the challenges facing palliative care internationally? I have read that palliative care can be difficult to provide in developing countries that lack access to opioids.

Also, how do you think the field of palliative care will grow/change over the next decade?

poustinia
Great question. Palliative care in the US has grown by 148% in the US in the last decade. Across the world, it is growing slowly as well. The World Health Agency, for example, has called palliative care a "human rights issue". So it's coming along. And we do use opioid access as a surrogate outcome to understand the quality of palliative care across the world. For example, in some Eastern European countries, there is a daily limit to opioids that a person can receive, even if they're dying of cancer and have significant pain. The international palliative care community has put pressure on that government to reverse that stance, and slowly across the world some of these historical biases against using medications for adequate analgesia are starting to turn. For some countries, it's an issue of opioid availability (the government controls access and does not import any into the country); for others, it's about patient's accessing the medications from the pharmacy.

Hello, Dr. Kamal - thank you for doing this.

As a medical student, I was wondering what you feel are the main misconceptions of palliative care within the medical field itself - that is, what is it that even fellow physicians in other specialties tend to get wrong about palliative care? And similarly, what do you think that other physicians should know so that they utilize the services of palliative care physicians properly for their patients?
Great questions, and good luck with your career. In my experience, too many people in healthcare (not only physicians, but very well-meaning nurses and front-desk staff) get hospice and palliative care mixed up. They assume that if a person is receiving palliative care, the person must be dying - or that a person should only receive this care if they have days to weeks to live. Just not true. Look at Temel et al. in NEJM from 2010 where they show a survival benefit of almost 3 months for patients with advanced lung cancer (median survival 14 months).

Currently, 66% of all hospitals have a palliative care team, and they are often underutilized. What other physicians should know is that these teams are there, and ready to help in whatever way makes sense.

Can palliative chemotherapy in cancer patients ever result in 'cure', however remote that possibility is?

Certainly, there are Stage IV cancers that are still curable, such as some colon cancers and melanomas. But these are the exception, and certainly not the rule. Palliative care certainly does not try to get in the way of those successes, but also helps patients match their wishes and preferences with the right care.

Does this type of work ever get to you emotionally, and how do you deal with burnout? What is the most difficult case you've ever had?

Regarding a difficult case, it was a young adult in his early 20's with an incurable brain tumor. He was ventilator dependent for breathing, but could still think, communicate, and interact. He made the difficult decision to come off the ventilator, which would lead to his death. He died peacefully in our ICU, surrounded by his family, after making that decision.

Regarding burnout, we recently did a study which showed that 66% of palliative care clinicians do report some amount of this. It can be a difficult job, and each clinician has their own way of handling it. We are working on a resilience training for our colleagues, but there aren't many formalized programs to address this in palliative care, or across medicine. I personally make a diligent effort to step away and detach between my clinical responsibilities, but that can be hard. Also, I speak with my colleagues often and we share stories and ways to process through the difficult things we see. It's not for everybody, but not as gloom and doom as it may seem on the surface. In fact, it's very rewarding work, because patients and families are so tremendously grateful for our presence during times of crisis and uncertainty.

Dr. Kamal, recently, the subject of assisted suicide has become a hot topic after its legalization in California. How do you see the role of the physician in Death and End of Life Care? I know many doctors are uncomfortable with the idea of prescribing death, and how their role in society would change if they became the first option for people who want to die.

In these situations, how would you distinguish between people who are near the end of their lives and physically unable to care for themselves, and people who are in psychological pain, and a patient with untreatable chronic pain?

Lastly, do you feel that our resources are appropriately distributed to palliative care, where they might be more efficiently used in, say, preventative medicine?
Regarding resource use, the mortality rate for any individual is still 100%, so that high quality end of life care is truly a public health issue. It doesn't mean others aren't, but despite 90%+ people wanting to die at home, only about 50% actually do.

Regarding physician assisted suicide, I personally have never been asked or live in a state where it is permitted. I do believe that most, if not all, issues of distress can be addressed without this, but do understand that certain issues of existential distress may require something more. Often, we find that "untreatable" is really a conclusion made before all options are explored or exhausted, including psychiatry, anesthesia/pain, psychology, chaplaincy, and others.

What are your policies and practices when using narcotic drugs on a terminal patient? I.e. is it up to the patient if they are conscious? The family? I know when my grandmother went, she was on massive amounts of morphine and seemed happy. I was glad that she wasn't in a huge amount of pain, but in the last 10 years there has been a huge movement by the DEA to criminalize doctors who prescribe these kinds of medications and I know for a fact that it has affected their willingness to prescribe narcotics to normal (non-pallative) patients, I'm wondering if it has also affected the way you prescribe?

EWbroWTE

It hasn't, really. As long as physicians regularly see and evaluate patients, document accurately about their decision making, and match needs to interventions, there aren't legal issues. The DEA is going after those who don't do any of these due diligence pieces. Opioids (narcotics) are among the most common medications we use, because pain is the #1 symptom felt by dying patients.