So thanks everyone for coming back I’m glad to be here. I was here 2 years ago speaking on some different topics. Before we get started I was wondering if I could just ask who among us, and if you could raise your hand, performs capacity assessments on their patients on a fairly regular basis as just a natural course of their practice? Could you raise your hand if you’re doing capacity assessments? Okay alright thank you.

This is going to be a fairly straightforward talk. I think that the principles of assessing decisional capacity in anyone, or in an older adult, are fairly straightforward. I’m going to try to keep this a straightforward talk that you can come away with some basic points. I think where it gets more difficult is on tricky cases where you’re trying to apply the principles and you’re unsure to what extent your own biases might be creeping in or people are kind of on the fence between whether they could be impaired in one domain or another. So these are the goals of the talk today. We’ll start by just making a distinction between global competency and decisional capacity. We’ll talk, we’ll spend a brief amount of time on the prevalence of incapacity in different sorts of clinical settings, we’ll go over the 4 key elements that we need to investigate when we’re assessing someone’s capacity to make a specific decision. We’ll talk about his concept to the sliding scale and the burden of proof that a patient demonstrates that they have the capacity to make a given decision. Then we’ll talk about tools that are available to clinicians free online that they can use to guide them if they would like more support in their capacity assessments. Alright?

So here’s the first part, let’s just establish some basic definitions. A competency determination is outside the domain of what physicians or healthcare providers do and it’s helpful to think of this as
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JAMES TEW, MD

global competency. This is something, this is a legal term, it’s a determination made by a judge in a court, and it’s all or nothing alright? So if a judge determines that you lack competency, you have lost your legal right, your right to make any sort of decision for yourself. That’s not to say that people won’t allow you to make decisions but it means you no longer have the right to make those decisions. And by definition if a judge is taking away that right as part of that same proceeding, someone has to be identified to serve as your surrogate, that’s your legal guardian.

So these are, so when people talk about competency they sometimes use that interchangeably with capacity, but technically this is what competency is. Now decisional capacity is a much more circumscribed thing. It’s an issue of a single decision at a single point in time. And this is something that physicians and healthcare providers are primarily the ones responsible for assessing. It happens everyday in hospitals across the country or in clinics and it pertains only to one thing at a time. So a person can have the capacity to make a decision about one thing, but lack the capacity to make a decision about another. It can be fleeting, someone can be temporarily incapacitated and a common example is someone with an acute delirium that may resolve within a day or two and then they would regain the capacity to make the decision in short order.

So how common is it that we’ll run across people that are incapacitated in our daily practice? T depends on where you’re practicing. This is a very interesting article and I give you the full reference at the end, by Sessums it appeared just a few years ago in JAMA looking into what are the rates of incapacity if you assess people in these populations. As you can see healthy community dwelling older adults are rarely incapacitated with regard to specific decisions around their
healthcare. And the more medical support a person needs, the more supervision or ADL support a person needs, the more likely they are to be incapacitated. To the point where in Alzheimer’s Disease diagnosis, about 50% of the time these people are found to be incapable of making specific medical decisions about their health. It’s also worth noting that half the time they are not incapacitated. This brings us back to the point that everyone is presumed to have decisional capacity until proven otherwise. Sometimes it will be fairly obvious, sometimes it’s more tricky and this is the other thing they reported on in the Sessums paper. In pooled studies physicians missed the presence of an incapacitated patient about 58% of the time. So we may have a bias toward presuming people have capacity to make a given medical decision even when they don’t. What I found reassuring is that when they did, when physicians did make a decision that someone was incapacitated, they were usually correct. So it may be that when we apply the principles of the capacity assessment we’re pretty good at determining who is and who is not fit, but we may not do it consistently enough.

So now we’re going to break down the 4 main elements of the capacity assessment and you can go and look this up in various resources. It all boils down to these 4 basic elements. The first is does the patient have an understanding of the facts relevant to whatever medical decision they need to make in a basic sense. And the second one is based on those facts the risks, benefits and alternatives of the treatments available to them, can they appreciate the consequences of those decisions as it pertains to them specifically. So it’s not enough to say I understand I have a heart condition and that you’re saying that people with this kind of heart condition need this kind of procedure or they could have very bad outcomes. But if you can’t apply that to your own self and say but I think I’m going
to be fine for example, we could have a problem there. So and we’ll go through each of these points individually. So understanding of the facts relevant to your case and the consequences as they would affect you and then logical manipulation of the information involved. So that you’re not just parroting back where you have the physician or a care provider saying this is what’s going on do you understand and you say yes. This is what’s going on do you understand it and you just say yes but you’re never really demonstrating that you can work with the information yourself. And lastly the ability to communicate a choice. You may understand risks, benefits, and alternatives, you may understand the consequences and be able to work with the information but if you don’t have any way of communicating that, or you refuse to communicate that, that in and of itself could be a sign of incapacity. You have to demonstrate that all 4 elements are intact. Failure of any one of these elements could be a sign that you’re incapacitated.

So let’s start with the first element. A factual understanding of the issues, this is why we engage in informed consent. We presume people can apply the facts of their case, weigh them against their own personal values and make appropriate decisions. So they must understand their illness and the purpose of the intervention being discussed, risks, benefits, and alternatives of these different treatment options including what would happen, or what’s likely to happen if I forgo any treatment. Now this is important because we may, as clinical care providers, have a very specific and nuanced understanding of the health condition that they do not necessarily have to be able to feed it back to us at that same level of complexity. So I might say to someone you have a problem with the left anterior descending coronary artery and it’s a 95% occluded and start using a lot of jargon where as what might be sufficient is they say I am here in the hospital because I have a problem with my
heart. So questions that we would elicit this first for factual understanding, we might ask so what is the problem that you’re having now or why are you here in the hospital. If they can say I’m here because I have a heart problem and it’s pretty significant, that may be enough to start suggesting they understand that they have a problem here.

Then if they can give you a basic understanding is what is the procedure or the intervention we’re suggesting. We are suggesting a catheterization or we’re suggesting a bypass surgery, what is the likelihood that this is going to benefit them and what are the risks of they forgo and they have to know that that’s an option, that they could forgo the treatment. Now understanding the facts and the consequences as they apply to them is actually a different kind of thing and it helps to give examples so I’m going to walk through some examples that I’ve come across in my clinical practice, I’m a geriatric psychiatrist. I work exclusively in hospital settings and so I’m having to assess capacity almost on a daily basis.

So example one, this is a real case that I’ve had. I have a tumor, you’re saying I have a tumor it’s invading my brain and it’s but scientists say people don’t use most of their brains so I’ll be fine, ill just use the rest that doesn’t get invaded and that was logic right? So the person is not debating that they have a tumor, not debating that surgery is needed to remove the tumor, but when they try to apply the consequences to what does this mean to me, they really fail.

Another one, I understand as an a geriatric psychiatrist you know safety of driving and does this person know whether it’s okay for them to drive is a very common issue. I understand I’ve caused 3
auto accidents in a week, I get confused behind the wheel. But it’s fine because I’ll be careful. This is a very common argument you may in someone who is really struggling with the idea of losing their license. They may not debate that their skills are waning, but they may not be able to accept really what are the implications for them, it may be too difficult.

And here’s another example. I understand that refusing amputation of my gangrenous leg will shorten my life but I value quality and not quantity and I’ll be honest with you, I’ve never understood why people like myself with end stage diabetes go through just repeated amputations, losing parts of their body, I don’t think that’s what makes a quality life for me. And in that case, you know this seems, there’s some intact understanding, some intact logic that there are real consequences of forgoing the treatment and it may be consistent with their values. They do understand the implications of this, for a shortened existence.

And let’s talk about rational manipulation of the information. If you read articles on capacity assessment some people call this their chain of reasoning and it’s how we apply the risks and benefits against our own values, our own healthcare values alright. So examples of that would be your starting point, your values have to be consistent with how you apply the potential outcomes of your decision and I’ll give you examples. So like in the last case, I value quality of life above quantity, refusing surgery may shorten my life, but the bottom line is for me that being disfigured by an amputation is not what I want for me and I see my prognosis is poor either way. There’s some intact logic there right? This person’s value system and how they get from that to their decision seems to be coherent. And then we have another case and this is a case that I’ve kind of dealt with
before, no matter what I want to live and I know that I need surgery to live, but the surgery will leave me horribly scarred and I simply can’t accept that and so I won’t have the surgery. Now this person may have an intact logic behind this but they haven’t really demonstrated it well here. Their superordinate rule is that they want to continue living but then they seem to supplant that with something like scarring and so this requires more exploration. Is this a person who really wants to do whatever it takes to, would support doing what it takes to live longer but say fear of the procedure or its consequences is causing them to waffle back and forth.

Now communication of a consistent choice, this is the final element. Some barriers the patient is incapable of communicating and we have gotten consults like this in hospitals. The person is on a ventilator and unconscious, obviously that person fails in multiple areas, they have an aphasia and they have difficulty communicating but they can understand information or they have a locked in syndrome. So in these cases where someone has difficulty with communication you need to do what you can to overcome barriers. Sometimes you need to bring in a speech therapist or a speech pathologist who can help them use sort of a touch type keyboard or word chart so that they can communicate with you even if they’ve lost their ability to do so verbally. We do have cases where a person will simply refuse to tell you what they want, they’ll be mute and those are tough cases where we may not then be able to act in accordance with their values. This is a tough one. Someone who repeatedly reverses themselves, they vacillate and go back and forth. I’ve had a case like this where a person had a wound, a long standing lower extremity wound, this was a nurse and she was very good at wound care and was managing at home for years, but she was getting closer and closer to the point where she was going to have to decide on an amputation and she acknowledged that
amputation eventually was inevitable. And when she would get fed up with trying to do the wound care and as her leg got worse, she would talk with her doctor and they would decide it’s time now and she would come into the hospital for a surgery, but then right on the, at the moment of truth, she would say no, no, no, no never mind, I want to go home, I’ll just keep working on my leg, I don’t wan the surgery and this happened twice. And at some point the primary team became concerned, does this woman really have the capacity to make this decision or is she so paralyzed by fear that someone else needs to make it for her. Now this kind of vacillation I’ve said you determine whether someone has the capacity to make a consistent choice based on whether you can act on their choices before, whether there’s enough time to act on their choices before they flip flop back again. So here the critical issue is timing. How urgent is it? What is the risk that she’s going to have a catastrophic health outcome if she does postpone the surgery once again. In her case even though it was very frustrating that she would come in and then change her mind go home, and then come again later, change her mind and go home, we realized we still had time. There was time for her to do some therapy around what does it mean to you to lose this leg, you know what are the implications. What kinds of preparation would you need to go through in order to be more comfortable with this inevitable decision. And so there was no need to declare her as incapacitated and then proceed with the procedure, we had time to work through this more. When you have people who are very ambivalent high stakes questions that often is what you end up with. We don’t have to make the decision right now there’s time to continue working with this person.

All right, and here's an important issue that sometimes we, I as a provider can lose sight of. We may have people who are making very difficult decisions and it's clear they are employing flawed logic,
all right. So I had a patient who was essentially in lay people's terms was essentially a hermit, did not like to spend time around other people, worked a night shift and really avoided even his own family who had a facial tumor that was growing. And ultimately was concerned enough by the size of the tumor that even this individual who avoided doctors at all costs came into the emergency room essentially saying I need something for the swelling, I just want to bring this down a little bit. We obviously the emergency room doctors were concerned, they persuaded the person to go for a biopsy and sure enough it was cancer. An imaging study was performed and it's a cancer that's invading the skull.

Now this person insisted I understand you have, you do your doctor tests, I understand you have your opinion that it's a tumor, I'm not going to debate that; but I think it's a bee sting. And I think over time the swelling will go down and really I just came in to get something for the swelling, like a cream or something. You know I don't want all this stuff that you are talking about. And naturally our first impulse as providers was to say oh my goodness, this man has no idea and we can't persuade him to understand the seriousness of this health condition. And he's going to go home thinking he can put some ointment on it and he'll be fine. And we almost leapt to the decision that what that means is he's incapacitated and obviously he should have the surgery. And we need a surrogate decision maker who can understand. But we took our time with the decision and we realized that even if this man understood that this was an invading facial tumor it is highly likely that he would have decided not to pursue surgery anyway, all right? Based on information we could gather from the family this is a man who did not want to have anything to do with healthcare providers, who valued his independence and privacy more than anything and the fact of the matter is
most of his face was going to be removed to save his life, right, most of his mandible, his ear, part of his you know his jaw and possibly his entire nose was all going to have to come off. And that probably would have put him - he was never going to eat again. And this kind of a massive - this kind of a massive change may have been something that he would have even if he understood said that's not what I want. You know I want you to provide me with some support but I don't want to spend the rest of my life in that kind of a situation.

All right, so it's important that we even if we determine that someone is incapacitated we try to make sure we are acting in accordance with what we can ascertain as their values, all right, and not do things to people who are incapacitated based on what we think is right. And whenever possible we want to try to preserve that autonomy, we don't want to overrule people's values.

Okay, this is a term I came across in reading for this talk that I thought was fascinating, it's not necessarily one that's used commonly but I would say be very wary of pseudo incapacity and I would say as a consulting psychiatrist when I was on the consult service in our hospital I would come across this not uncommonly. A person where we were brought in because there were concerns they were incapacitated going into some sort of surgery, usually a major procedure, and we would go in and they just seemed not to understand what was going on. And they'd ask us is this person incapacitated because they are saying they don't want the procedure?

And what we'd find is they simply lacked enough information, right, and I don't doubt that the primary team was trying to provide the information or believed that they'd supplied adequate
information but a lot goes on for a person when they are in a hospital facing big decisions, right? It's scary. When you are confronted with major life altering news your amygdala lights up, your frontal lobes shut down and you are just not receiving information very well. So sometimes we would have to go back to the primary team and have them help explain this again in as simple terms as possible in a way that this person could understand and then we'd realize the person was equipped to make the decision, all right. And in those cases we want to be careful, we lose sight as clinical providers, we can get very jargony, right? And we sometimes will fall back on overly intellectualized explanations of things when we are uncomfortable that there is - you know that this is a very devastating diagnosis or a devastating prognosis. And then another thing, this goes without saying really, if a person is overwhelmed especially an older adult who may be losing their ease of use of English as a second language try to see if you can find a translator or revert to the primary language when possible.

All right. So this is more of just a practical consideration, so who is the surrogate decision maker for our older adults who lack capacity? Obviously if a judge has appointed a legal guardian that's who we go to, power of attorney or people familiar with the distinction between the power of attorney and a guardian. Power of attorney is someone who you when you have sound mind designate I want that person to be my surrogate decision maker in the future if I become incapacitated. All right, so that's they chose the person and the guardian the judge chose. Usually you have to pursue a guardian when no one has been designated until after the person has already become incapacitated or incompetent.
And then there is actually a hierarchy of family members, at least in this state I believe, so it starts with a spouse and then it goes to adult children and so on. And of course it's ideal when the family is in agreement about what should happen next, they have this concurrence about what their loved one would have wanted but sometimes there can be polar opposite interpretations, sometimes there can be vehement disagreement. And I think those are very tough cases and you as a physician should not be on your own trying to resolve that level of conflict. Remember to reach out for help okay? So it's in these cases you should be consulting with you know a medical ethics consult or a psychiatrist to see if you can get some backup in distinguishing who should be the appropriate decision maker, or a hospital attorney. And then lastly it's interesting to note that when there is no viable, you've tried and you can't find someone, healthcare providers can be on that sort of - sort of on that list if you go low enough as the person who makes the surrogate decisions.

And then there are rare cases where a surrogate decision maker even appointed by the courts or a power of attorney there are concerns that that person is not going to act in accordance with the values of the patient. This is a very sticky situation, sometimes our surrogate decision makers come right out and say it, they say this is what my dad would have wanted but I can't tolerate that. I think what we should do is this. And that usually you need to provide more education and a lot of support for them, right. Dad would not have wanted to be on a ventilator ad infinitum like this but I just can't bear to let him go. That person needs a lot of support. You need to help them understand their role, right. Your role is to advocate for what dad wanted. All right?
Okay, now there are a ton of guides and aids out there for helping clinicians in their capacity assessments. In fact I think there is - there is close to 20. And I think that just speaks to how straightforward the basic principles are. But in the paper by Sessums they recommend this one, the aid to capacity evaluation, please don't read all these, and the criteria they used were this. One, it's free and it's available online, all right. It's been validated, it holds up well. People who use this tool it holds up well against the so-called gold standard of the expert opinion say from a psychiatrist. And it uses the patient's own clinical scenario to assess their capacity. A lot of these that are listed here have the patient go through a hypothetical situation with another patient and see if they are able to identify what would be sound and unsound reasoning and they believe that that's actually a violation of the whole idea of the contextual nature of capacity, that it really is focused on your specific situation and decision. And if you Google this, Google this tool you'll find that it's on websites, a number of websites I think I have the reference on my last slide, I'm not sure.

Now I mentioned I bring up the sliding scale of decisional capacity and that's basically that not all decisions are equal, and decisional capacity is less relevant when the consequences of the decision are less significant, all right. So a decision like do I want yogurt or cereal? It's almost irrelevant whether I have the capacity to make that decision because the risks yogurt versus cereal are essentially nil, right? Should I skip the last two talks today? I don't know who is giving the last two talks you know. I would say that's a very risky decision, you could miss out on tremendous information. Your patients will suffer, all right. All right, should I watch TV or read? You get the idea. Should I buy a new car? Stakes are potentially more worrisome right. Should dad or should
my brother really be going out and buying a new car? Does he understand whether he has resources?

But then this is clearly different, right. Should I have a transurethral resection of my prostate? This one where we spend time, okay. And similarly if a person has a legal guardian and they've lost the legal right to make all these decisions we may think it's irrelevant and just allow them to be autonomous around cereal or TV or whether they attend lectures, and then we start invoking guardianship and surrogate decision making in these tough cases where there could be very, very significant consequences. All right. So obviously the more potentially damaging or peculiar the decision the more we have - the more the patient themselves has to do to clearly demonstrate that they have the capacity to make this decision. All right, okay.

Some important points, I think I already addressed this. People are presumed incompetent until an assessment indicates otherwise. And this is one I don't know - I assume people are aware of this. Any physician and in some cases any healthcare provider can at least perform a capacity evaluation or capacity assessment, it does not have to be a psychiatrist. However if you are in really tricky situations where you are questioning if someone has a profound depression and this is influencing their decisions, psychosis, right, or if you just think it's a gray area case don't hesitate to reach out and get support. You should not be on your own on this if you are uncomfortable. So use your comfort level as a gauge, all right.
Let's review the 4 basic elements of decision making capacity. Can they understand the facts? Can they appropriately apply those facts to the consequences they will experience for a given decision, treatment versus nontreatment? Can they rationally manipulate the information so they are not just parroting back to you? And can they effectively communicate a choice? And can they consistently communicate a choice even when there is no significant changes in information? All right.

Okay, the goal is to ensure people are making decisions according to their values, not ours, not other people's but their own values. And don't hesitate to bring in an outside consultant be it an ethicist or a psychiatrist if you feel that the information is just - if it's too murky, all right?

These are some of the references I would recommend. Sessums and colleagues, JAMA 2011. Paul Appelbaum, New England Journal of Medicine 2007. And here is a link for the Aid to Capacity Evaluation at the University of Toronto Joint Center for Bioethics. Okay.