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8-15-14_DR. PAUL HAN

00:00:00 CHELSEA PROUGH: Thank you for participating in the Decision Making Steering Committee Speaker Series. My name is Chelsea Prough and I will be moderating today's webinar. I would like to introduce this morning's speaker, Dr. Paul Han of the Maine Medical Center. Dr. Han will discuss his personal experience as a practitioner and what he identifies as the most challenging issues in cancer prevention and treatment.

00:00:29 At this time all participants will be in listen only mode. Please note that this webinar is being recorded. If you have any technical difficulties or questions, please enter your question in the chat window so we may help you. I will now turn the call over to Dr. Han.

00:00:47 DR. PAUL HAN: Thanks Chelsea, and good morning to everybody and I just wanted to thank you for the opportunity to talk to you today about a problem that I see as a pretty major challenging decision making issue in cancer care.

00:01:06 And I've titled this talk shifting gears, the transition from curative to palliative treatment

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goals. And I'll talk a little bit more about what I mean by this sort of idea of gear shifting, but I see this as a really major issue, at least from my perspective as a palliative care physician, and to give you just a couple of sentences about my clinical background.

00:01:30 I trained as a general internist and practiced general internal medicine for many years. And then subsequently became involved in palliative medicine and was formally at the University of Pittsburg, which at that time was one of a handful of palliative care programs in the country. This was in the mid 90's.

00:01:50 And I spent a lot of time doing palliative medicine and since then as my NCI colleges know I've kind of shifted my career more into research although I am, I'm still active in palliative care and work with in-patient Hospice program here in Maine.

00:02:06 But what I'm going to do today is really kind of talk to you about a couple of cases. I really structured this talk, so to begin with a couple of cases that illustrate this problem of gear shifting. And then

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I'm really going to talk about some questions and interesting problems, I think, that this, this challenge brings up for us.

00:02:32 More in the spirit of exploring this area as a problem space and raising questions rather than answering questions. And I'm not really going to present any data per se, but really just kind of talk about this problem as a potential research direction and hopefully we can engage in some discussion about what future directions might be to try to shed light on this issue.

00:02:58 Next slide please. So, what I'm going to do today is a couple of things. My objectives are to really first talk about what, what I mean about this transition from curative to palliative care, goals, and cancer treatment. And then again to talk about some future research needs and there's where I hope we can engage in some good discussion with this. Next slide, please.

00:03:28 So, I'm going to start with a case, and both of the cases, there's actually two cases I'm going to talk

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about, both of which are real. This one is now several years old from some formal experience of mine, but I'm hoping that they will kind of illustrate in some detail of the nature of the problem that we're talking about.

00:03:49 So [inaud.], was a 68-year-old man with advanced bile duct carcinoma. He had been through multiple cycles of chemotherapy in the six months prior to the time that I had become involved in his care. He had progressive disease. This is a really bad disease, as everyone knows.

00:04:09 He had progressive decline in his functional status over the several months before his hospitalization. He had been in and out of the hospital with multiple complications, including infections of various kinds, dehydration, intractable pain, and he had - his major symptom issues were ascites and peripheral edema.

00:04:30 He is also becoming progressively more jaundice. At the time his primary oncologist decided against further chemotherapy and this was actually the reason that the palliative care service was consulted. The

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hospital chart note, and in that note the oncologist basically said that there was nothing for me to do. And he had requested palliative care service consultation specifically to discuss a change or the transition in his goals of care, the patient's goals of care and was asking the palliative care service to then assume primary responsibility for this patient's subsequent care and also to discuss and initiate Hospice care.

00:05:11 Next slide, please. So, we had seen the patient in consultation and had an initial discussion with he and his family, who at the time disconcertingly to us, they were completely unaware that this decision had been made to sort of transition from what had been cure focus treatment to palliative, a palliation focused treatment.

00:05:40 They were very disappointed that further chemotherapy was not going to be offered. And upon our initial conversation with them, you know, again in the text of this kind of shock and surprise, they really refused any kind of consideration of Hospice care, there were

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really reluctant to switch the goals of care from cure to palliation.

00:06:04 Over the course of the next several days we had several more interactions with the patient and family and I think just as a process of gaining trust and getting to know one another went on, eventually we were able to discuss the patient's overall condition, his prognosis and the overall goals of care and they came to see and I think to judge on their own that it really made sense to really have a shift in plans, to sort of shift gears to palliation as a primary goal.

00:06:40 They did agree to Hospice care and the patient was subsequently discharged home, four days after the initial consultation. The palliative care service, pretty much took over the primary management of the patient at that time, and then he died several weeks later at home, in the home Hospice program.

00:07:02 Next slide, please. So, the second case was a woman who had metastatic breast cancer that was diagnosed two years prior to admission. She had at the time been through high dose chemotherapy and bone marrow

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transplant at the time of that being one of the treatments of choice for her disease.

00:07:27 She had experienced a new disease reoccurrence about six months prior to admission, which was treated with chemotherapy and radiation. Her more acute problem about one month prior to admission was the new onset of cortical blindness, which was secondary to a left hemangioma carcinomatosis. She had undergone whole brain radiation and now was admitted with increasing confusion, declining functional status, basically failure to thrive.

00:07:58 And her physical exam and her lab findings were all notable for severe dehydration, malnutrition, profound weakness, and basically all of her lab indices were consistent with her declining very rapidly. Next slide, please.

00:08:23 So, she was initially treated supportively. She received IV fluids and also a nasogastric tube feeding. Her pain and symptoms were managed. Her primary oncologist had recommended to the patient and the family further intrathecal chemotherapy, although

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the oncologist acknowledged that there was a small chance of benefit but felt strongly that this was the right further for the patient.

00:08:50 The patient and her family, however, were very undecided and were actually questing the benefit of this, given how she was doing poorly and declining and her really rapidly deteriorating quality of live, and they questioned whether she could withstand further chemotherapy.

00:09:06 The patient's primary care physician requested a palliative care service consultation to try to kind of mediate and figure out with the family what they really wanted and to kind of assist in the decision making process. Next slide, please.

00:09:27 So there were subsequent team meetings that were mediated by the palliative care service and including all of the people involved with this case including the patient and family as well as the internist and the oncologist. After a series of meetings, not just one meeting, it was finally decided to post-pone any further chemotherapy.

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00:09:47 The patient was discharged home with visiting nurse support, not Hospice care, and tube feeds were considered. Her functional status continued to decline over the next couple of weeks. The oncologist still was recommending further chemotherapy, for which the patient subsequently refused and then home Hospice care was initiated and she died about three weeks later at home.

00:10:14 Next slide, please. So, you can see from these two cases how difficult this whole transition from curative to palliative treatment goals really is in real life. It really is a major shift in gears from targeting all the therapy towards fighting disease, potentially curing the disease, and prolonging life, to actually living with the disease and relieving suffering.

00:10:52 That's kind of a - those are the [inaud.] that I think a lot of people talk about and even though we talk about these all the time, it's really an extremely difficult transition to make when you're actually in the thick of things and trying to do it. I think,

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from my perspective, I think it's one of the hardest things that clinicians of any type, whether you're treating cancer, or other life limiting illnesses, it's probably the hardest thing to do, is to shift gears.

00:11:22 Once everybody is sort of on the other side and saying, okay, you know, we realize the prognosis is very limited and we realize that cure focus therapy is not going to be successful or has a very low chance of success and let's focus on palliation, let's focus on Hospice care, once you're over that hump and on the other side, I think things are relatively speaking. They're easier, but it's really that transition point. That shifting of gears, that extremely difficult.

00:11:54 And as these two cases illustrate, it's difficult for patients and families, but it's also difficult for physicians as well. So the question is, why is this the case? What is it that makes this so difficult? Next slide, please. Well, there are a lot of reason why it is difficult and I think they're all pretty obvious to us.

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00:12:16 But I think it's helpful to try to think about these in an organized fashion. And to start with these are a couple of the barriers that I think get talked about the most, when people discuss this whole problem of transition. There are certainly widespread structural factors that are kind of built into the very fabric of healthcare that really favor this, what some people call the therapeutic imperative.

00:12:45 We know that there is, in this country in particular, and over supply of resources for intensive care focus care. And at the same time there has at least historically been and undersupply of resources for palliative care and Hospice care as well. All of these resources have been vastly underutilized, at least historically.

00:13:09 So the solution to this barrier is something that has really attracted a lot of attention, particularly in the last decade or so, and since the time when I started doing palliative care, we've come really a long way and not palliative care services for example are all over the place. It's hard to find hospitals that don't have a palliative care service.

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00:13:32 Whereas I think at the time when I first got involved in there were about five or six programs nationwide, and now there's fellowship programs, there's specialties and certification, etcetera. I think Hospices, and Hospice utilization has also increased although still we have a ways to go, but we've also come a long ways since the mid 90's even.

00:13:56 And there's been a lot of work done to increase access to palliative care and Hospice care. But also, more fundamentally to shift our thinking and shift the who care delivery model towards the idea of more integrated and earlier [inaud.] palliative care. Next slide, please.

00:14:19 So, this is not a brand new idea. Back in the late 90's the institute of medicine defined palliative care expansively and they specifically noted that palliative care in this broad sense shouldn't be thought of as being restricted to people who are dying or clearly at the end of life for people involved in Hospice programs, but it really is a more global fundamental approach to care that can exist alongside

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and integrated within cure focused care as well. Next slide, please.

00:14:53 So, more recently Jennifer [inaud.] and her colleagues, this is a nice paper in the [inaud.] Journal of Medicine have conceptualized this visually and others have done this same diagram also in the 90's and early 2000's as well, but looking at the figure at the top of this slide, this is kind of this sort of rectangular, kind of box oriented figure is kind of helps you visualize the traditional way of thinking about the difference between cure focus care and palliative care.

00:15:39 And I think traditionally, and probably in a lot of people's minds this is a dominate model and a powerful model that okay we keep doing all the life prolonging and curative treatments and to think about the first case that I told you about, how the oncologist said, okay, I've done my chemotherapy, now there's nothing for me to do and now we should focus on palliation and get somebody else involved in the care.

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00:16:03 He was in particular, I think, working from this model. Whereas where we ought to be and where a lot of people are advocating that we be is in the rectangle on the bottom part of this figure where we view cure focus care and palliative care as really being integrated with one another.

00:16:21 We move the model of palliative care upstream, so that it clearly has a role, even at the earliest phase of diagnosis, granted the role might be smaller because the patients have less pain and symptom burden for example, or they're not close enough to death that there doesn't need to be more intensive palliative care services provided, but the needs increase over the course of care and as the patient approaches death.

00:16:52 And so that's the idea of this whole notion of integrated palliative care, earlier palliative care and this is a model really that I think the IOM was talking about as well back in the late 90's. Next slide, please. So, another set of barriers that I think is [inaud.] just as widely when people talk about why we have trouble shifting gears, and that is

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patient and physician factors. And there clearly we don't do as a good enough job as we should in advanced care planning and discussing goals of care with patients.

00:17:36 And clinicians and patients don't engage in these conversations enough and early enough so that often when patient decline, and they decline acutely or rapidly as indications that I presented earlier, it becomes a crisis situation. Where all of a sudden people are having these intensive conversations and there is a lot of confusion and emotion that happens and it makes these conversations a lot more difficult.

00:18:05 So, there's a big movement, there's been a big movement to try to make these conversations directed towards advanced care planning more common and to make that happen earlier and to improve both patients and clinicians skills in having these conversations and that's been an extremely important movement. There's also the sense that there's a lack of knowledge about prognosis.

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00:18:30 Not only among clinicians, but also clearly among patients. And often prognosis doesn't even get talked about at least explicitly, it doesn't get thought about at least explicitly and there's been a lot of effort to develop decision support interventions that help not only estimate prognosis but to make prognosis more explicit to patients.

00:18:58 And Thomas Smith has been one person who has done a great deal of really great work in this area as well. And then there's the whole denial thing, and that's something that you really hear especially if you're listening on rounds and you hear doctors and house staff and others talk about patients, this always comes up.

00:19:21 You know, the patient just doesn't get it, or the family doesn't get it, and we've told them about the prognosis but they don't get it because they're in denial. And that's another kind of big barrier, that I think clinicians will tell you gets in the way of this whole gear shifting that needs to take place. Next slide, please.

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00:19:45 So, I think though that first of all we have [inaud.] of all those barriers and solutions we just talked about are important, and there's just been lot of progress that's been done, good progress to really try to overcome those barriers and we've come a long way with that.

00:20:05 Having said that I think from prospective there is the really bigger and deeper problems that to me are less tractable are these. And first of all the uncertainty that surrounds all attempts to estimate prognosis and then secondly optimism bias. And to me these are more fundamental, maybe less tractable problems that we still haven't figured out how to deal with, and I'm not sure they can really be solved, but the question is how can we manage these. Next slide, please.

00:20:45 So, starting with prognostic uncertainty, there is first of all, this is something that first of all arises from our difficulty in just determining prognosis to begin with. It's true that historically we've just had very limited prognostic evidence.

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00:21:05 So, our uncertainty in prognosis really arises, it's a knowledge problem. We just don't know enough to estimate prognosis accurately. Over the last decade or so, there has been a proliferation of clinical prediction models or statistical prognostic models to help us do a better job at this and there have also been more and more studies cropping up to look at outcomes and help us to estimate the prognosis of patients with much greater accuracy and even at the individual level some would argue.

00:21:39 And yet there is also, the irreducible uncertainty that will still exist no matter how accurate we can make our prognostic estimates. Even if we develop these [inaud.] models that tell us pretty precisely what the aggregate level expected frequency of death is in a particular patient population, we will still never know at the single event level, at the individual level will this person fall into one category or another, the living or the dying.

00:22:18 And that kind of irreducible [inaud.] uncertainty that really arises from the kind of fundamental indeterminacy of future outcomes will always be there.

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And when you talk with patients, and I've had many of these conversations with patients, even if we think the odds are or, you know, your chances are one out of a thousand, there will always be that question, that legitimate question of, am I the one or I am the 999.

00:22:49

And that's something that we will never know. And if you talk to seasoned clinicians who have done this enough to have seen that one out of a thousand, that's kind of hard to get out of people's brains, as well, as it makes these conversations very difficult. It means that this type of uncertainty is really irreducible.

00:23:13

Even if we could have much more faith or confidence in the accuracy of our prognostic estimates we would still be left with a second problem of determining when the end of life period, which is itself a construct that serves its own purposes, but determining when that period begins is yet another source of uncertainty that is independent of the accuracy of our prognostic estimates. Next slide, please.

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00:23:49 So, if you look back at this [inaud.], and what I mean here is that even if we could, with a great degree of accuracy and confidence predict somebody's life expectancy we still would have a problem of determining whether we are the end of life or not, or when would it be appropriate to, for example, activate Hospice care, or to discontinue chemotherapy, or to initiate other either curative or palliative interventions.

00:24:20 Obviously because of the Medicare Hospice benefit in this country, which has drawn its own bright line, saying that physicians need - two physicians need to certify that a patient has a life expectancy of six months or less to even qualify for the Medicare Hospice benefit.

00:24:36 That's a bright line that has been drawn from a policy point of view, but patients and families and clinicians aside from that Hospice decision have their own ideas of whether dying is actually happening. Have they entered that end of life or dying phase. And this again to me is a separate question all

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together from what their precise life expectancy is.
Next slide, please.

00:25:08 So, the second problem, which is very closely related to this is what's known as the optimism bias and because I think Bill Klein is on the call as our other, has had much more experience with studying this phenomenon than I have, but it's essentially the inclination to over-estimate the likelihood of positive events in the future and to under-estimate the likelihood of negative events.

00:25:37 And this is something that's pervasive, as you all as an audience better than I, this is really a very fundamental cognitive illusion. But importantly it's also an adaptive cognitive illusion, and I like some of the work by [inaud.] who's kind of written about kind of the adaptive side of this, that it's an illusion, yes, but it protects us from accurately perceiving the pain and difficulties the future undoubtedly holds.

00:26:06 And I think what's key here is precisely the adaptive nature of this and the irreducible nature of this and

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this is something that [inaud.] argues. That even if we can acknowledge that it's there, we can't make it go away, and in some sense we have to have this illusion in order to just move ahead with life and not sort of kind of give up.

00:26:32 And there's many, many sort of life decisions and domains where this applies, but it's especially important in - when somebody receives a diagnosis of cancer and to even move forward with cancer treatment, and once you kind of get on that train and are moving ahead with optimism and hope, it's really hard to just stop the train or go down a different track.

00:26:56 And I think that this is what we're really contending with in making this transition. Next slide, please. So, to me what, as a clinician, I think what we're really dealing with aside from all of those other barriers that we've talked about and the potential solutions, you know, structural problems, the oversupply of cure focus care and treatment, under supply of palliation focus treatment, we're also dealing with lack of information and knowledge.

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00:27:28 But if you take all of that off the table, I think what we're left with is fundamental irreducible prognostic uncertainty and there is this essential optimism bias that we - that sort of has to be there and that we can't just will it away or talk people out of that.

00:27:48 And it's the synergistic combination of these I think that magnifies this whole propensity against shifting gears, not only in cancer care at the end of life, but in all of healthcare, I deal with patients with life-limiting illness. And I think the underlying mechanisms here is that uncertainty really opens the door to other factors, to other motivations, you know, people, people kind of latch on to uncertainty because it gives them a chance.

00:28:17 And this is what I've seen in my own experience as a clinician and kind of talking to people about prognosis in general. And then the optimism bias also, it makes people less willing to acknowledge that they are even in the end of life stage. You know, even we can admit someone has a life expectancy, have

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we entered the dying phase, is it time to really shift gears.

00:28:42 And for both of these, these elements introduce this fundamental uncertainty that really favors the status quo, so let's continue with treatment. Next slide, please. Sorry. So, to me the big [inaud.] is that this failure to shift gears is not as simple as an issue of denial or misunderstanding.

00:29:13 I'm not sure how far and I don't think we can get very far, as far as we need to, simply by informing people about prognosis, I think that that will get us - we certainly have to do that and I think it will help, and I think there are cases, I've seen, where it definitely does help, but there are also cases where that's really not the issue.

00:29:31 And it also seems that because of the adaptive nature of optimism bias there is little we can do to simply make that go away. Next slide, please. But, I also think that maybe what we need to do, is think about these problems a little bit differently. That maybe

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the issue is not make them go away, because we can't do that, but to simply kind of change our approach.

00:30:02 The approach of ourselves as clinicians and also as - for patients to kind of reframe the problem and to not try to make uncertainty go away, or not to make optimism bias go away, but to acknowledge both of these as really fundamental, in escapable issues and phenomena that we need to deal with.

00:30:27 And to somehow adopt a mindset where we remain optimist, we acknowledge uncertainty, and yet at the same time we are adopting an approach that I guess builds in some contingency in case we're wrong. And one thing, kind of a catch phrase that the palliative care community has taken up, there are people like Bob [inaud.] and others who have written about this, are - its encapsulated in this phrase, "Hope for the best, prepare for the worst."

00:31:05 And many of us use this phrase very often when we speak with patients and try to get them to sort of come to terms with their illness and to plan for the future and I think that there's wisdom encapsulated in

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this type of thinking and what I'm just not sure about and what I think is a really important direction for future research is to try to understand how to do this and what's involved with doing this and kind of what are the mechanisms behind approaches like this and how can we codify it and make it more effective.

00:31:40

And here's where, as I began this talk, I was telling you, I'm not really going to propose any answers to anything, I'm just raising some questions, but in my mind some key areas of focus for future research are to understand how can we do this, and what all communication strategies other than this catch phrase can we use to promote this type of cognitive reframing, to help people really cope with a bad prognosis and to shift gears when it's appropriate and to help them feel more comfortable with that plan.

00:32:16

I think part of this comes down to relationship building and emotional support. And there are, obviously, various strategies, these are really key, essential functions in patient centered communication, and patient centered care.

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00:32:33 There are probably other strategies that I think seasoned clinicians do every day, but that have not been codified and studied and I think a lot more work is needed to really do that, to help us understand what are the best approaches and how can we help people with this whole gear shifting problem.

00:32:52 So, that's my last slide and I think we can - I'll leave it up to you all, but I think we can open this up for discussion if you'd like and I'd be happy to also take any questions.

00:33:11 CHELSEA PROUGH: Thank you Dr. Han. At this time I will turn the call over to Dr. Jerry Suls, Senior Scientist at the Behavioral Research Program. As a reminder, this webinar is being recorded. All lines will not be unmuted.

00:33:27 DR. JERRY SULS: Thank you very much, Dr. Han, for a very interesting gear shifting presentation. I have a feeling that a number of people on the call are going to want to comment, but to give them a little time, I want to first ask a question that is somewhat cynical

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and so - this is not my perspective, but I want to suggest it.

00:33:59 And is one of the things that is going on, is it possible that there are some economic incentives that also enter into this, with regard to continuing certain kinds of care as opposed to thinking about palliative or Hospice care? Do you think really that that's a fairly minimal factor in this process?

00:34:33 DR. PAUL HAN: No, and Jerry I don't think that's all really cynical, to put that out there. I think, I was perhaps reflecting my own optimism bias in terms of not mentioning that based optimism in terms of thinking about my fellow clinicians, but I think there is evidence about this and I think it's real, also that economic factors and economic self interest of clinicians I think is an important factor in kind of driving this continued push towards, you know, a cure focused treatment.

00:35:07 And, you know, I guess it almost goes without saying, but I think what I should have done was put that on my barrier slide as well, but I think it's - I'm glad you

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mentioned it and I think it's clearly an important factor, alongside all these other things as well.

00:35:28 In the cases that I mentioned, my sense was that that's not what was going on in the particular cases that I mentioned, but I've seen others where I have my cynical view as well. I think there were those kinds of economic factors that were driving decision making as well. So, I'm glad you brought that up.

00:35:48 DR. JERRY SULS: So, another question would be, I'm sort of asking you now to be a cultural anthropologist, which you're not, but I'll ask the question anyway, maybe somebody else will have a comment about this. Given the various factors that seem to play a major role in the fact that there's sort of this two rectangle approach and there's a need to move - to think more about the palliative care early on, are there other medical systems and/or cultures where things look more like what would seem to be the ideal?

00:36:40 DR. PAUL HAN: Umm, I think that's a good question. My sense, and I don't feel qualified to answer it

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actually, but my stab at it is that, you know, my sense certainly is that in Europe, they are probably closer to the idea than we are, you know, the Hospice movement was born in Great Britain and there are certainly countries in Europe that I think have a very different attitude towards [inaud.] even to the point of, you know, things like physician assisted suicide and things like that.

00:37:12 So, I think that there are clearly cultural differences, but I don't feel really qualified to answer your question definitively expect to say that I'm suspicious that they are closer to the idea than we are.

00:37:26 DR. JERRY SULLS: Okay. Could you say a little bit about what Thomas Smith's intervention looks like with regard to encouraging physicians for advanced care planning and/or moving folks, you know, a bit away from the curative to the palliative.

00:37:52 DR. PAUL HAN: Yeah, I can say a little bit. So, they've done some work and I don't think that they have published the definitive study, but at least some

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of their formative work to develop a decision aid that they give to patients, who are beginning chemotherapy and also with patients who are initiating palliative chemotherapy that basically presents patients not individualized but some aggregate level prognostic information on life expectancy and they've shown that this information is actually valued by patients.

00:38:29 Again, the definitive trail looking at how it influences outcomes and the treatment surrendered and cost and so forth. I haven't seen that, yet. But they've done at least some of their formative work, but it has shown that patients are receptive to this information. And that it seems to be valued by them.

00:38:49 DR. JERRY SULS: Okay. One of the issues with regard to the optimistic bias, and I think you're aware of this and just in time to talk about it, but in addition to the fact, well in addition that it's very prevalent and that it can resist the biasing, initially there were a number of folks who were concerned in the field that what the optimism bias could do is produce a kind of denial in patients or in even at the population level that they wouldn't do

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certain things because of this and there is some evidence I think to that with regard to people who are established smoker's, but there may be a kind of denial of the effects, somewhat.

00:39:45

But other researchers have found certainly with patient's and people under stress that the denial - the optimism is actually not just adaptive in the sense of keeping people's spirits up, but they're more likely to do adaptive things and actually make themselves more open to potentially useful information.

00:40:09

And that of course does in fact create the possibility of always thinking that there's a cure that's possible and is going to come into play. An ex-colleague of mine, Paul [inaud.] has shown in some research, which is mostly lab based, so we have to be careful not to go very - to generalize it very far, but, so far that the idea of being optimistic usually means that there is something you can do and if frequently that's something you can do is useful.

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00:40:50 Or it certainly it's not likely to hurt. It may be more likely to help even though the probabilities may be low and therefore for [inaud.] perspective an optimistic bias actually can be useful. But of course all that sets up the barriers that you're talking about.

00:41:14 DR. PAUL HAN: Right. Yeah. I mean I think you're raising really the most difficult issue, that optimism bias being manifest in end of life care. And I have to say I just have a profound [inaud.] about all of this, because I think in some cases, the optimism bias is all that's holding somebody together, and, you know, they're in the face of a terrible prognosis, like the second patient I was telling you about and in particular this is why they were, they were so tortured and I think that there is a kind of a mutual dance that goes on.

00:42:00 Because clinicians rightfully realize, like this patient's oncologist realized that optimism was all that was really holding her together and was almost too afraid to sort of suggest any other treatment, because she was worried about how that patient would

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react and would she be able to tolerate and [inaud.] in all that, so there's a sort of mutual expectation about somebody else's expectation that kind of feeds this kind of behavior.

00:42:35 And then the patient wonders whether, you know, they want to protect their doctor as well, and think that the doctor needs to be optimistic, so there's a lot of - there's some complex dynamics that go on here. But you can sort of argue that in both cases that I presented, it's so obvious, you know, the patient is going to die.

00:42:53 You know, why is there even an issue, this is just straight denial, this is what the intern would say, you know, they just don't get it, we just need to help them get it, but there is some potential damage to be done, I think, there, if we're just brutally honest and we just say, you know, you don't have any chance and we need to get with the program and do this.

00:43:19 And I just have a lot of profound [inaud.] with that approach and the sort of ethics of that. And I think it takes us to the heart of this difficulty that the

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optimism bias presents that you're right, you could argue that it's completely unrealistic and it's irrational and there's no, you know, it doesn't tie to any of that behavior, you know in any other way.

00:43:43 And yet, I think it's just profoundly uncomfortable to think about even trying to shatter that delusion, and to make it go away. And I'm not sure even if that's the right thing to do, and so my questions in my slide are meant as questions, because I don't know what the right approach is as a clinician and every case is a little bit different.

00:44:09 But even if you could argue that there is nothing to be done and there is no adaptive behavior that this would tie to, you know, etcetera, there's still prognostic uncertainty and there's still, I think, we all have some gut sense that there is something adaptive and good that maybe we shouldn't kill or try to kill about the optimism bias.

00:44:32 So, that's kind of a long-winded way, I don't know whether I'm making my point clear, but it's reflecting

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my own modeled thinking I think about this, but I still struggle with a lot.

00:44:46 DR. JERRY SULS: Okay.

00:44:47 BILL KLEIN: Hi, this is Bill Klein, can you hear me?

00:44:49 DR. PAUL HAN: Yep, hi Bill.

00:44:51 BILL KLEIN: Hi there, so I have two questions that are kind of related, one is when you look at the two rectangles in that slide where you showed that palliative care should be graduated as opposed to just being a little piece at the box at the end, I was struck by the fact that it's graded the way it is.

00:45:06 So, that you're starting off with more treatment than palliative care and then you increase the amount of discussion of palliative care over time and decrease the amount of effort devoted to treatment. But, I could imagine that someone could argue that that's not in fact the right model. But the right model would be for the rectangle to be half treatment and half palliative care, right from the very beginning.

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00:45:28 So, that, you know, it's equal effort devoted to each of the two, so that's one question I had, whether that's something that has been considered. And a related question would be kind of the temporal nature of this.

00:45:43 So, you said, "Hope for the best, prepare for the worst." Right? That sounds like a philosophy that would be relative at all points of the continuum, as one works through this. One can also imagine that it is sort of a temporal nature to this, so that you start off by hoping for the best and at some point, some reflection point, wherever that is, you start thinking about preparing for the worst a bit more than hoping for the best.

00:46:10 And I think that's certainly related to my previous question, which is, you know, should we be thinking about palliative care as much as treatment from the very beginning.

00:46:19 DR. PAUL HAN: Yeah, those are both really insightful observations [inaud.]. And in some ways maybe the

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reason why we're not at the rectangle you propose is that we're still stuck in that first box. You know, we're still thinking that there is this kind of, I don't know, there is this tradeoff here and so the compromise is to say, well okay at the beginning [inaud.] it's really mostly all care focused and we don't need to do much but they're going to kind of introduce [inaud.] ways to say, maybe that's reflecting the fact that we're still kind of conceptually stuck in box one and we're trying to rectify that in some ways.

00:47:06

But I think that you're right that, you know, if we really wholeheartedly adopted that kind of integrated view, it would be much more of an even, you know, split between those. And the whole point though, and point I'm trying to make in the one slide where I added the red [inaud.] is that at some point in our [inaud.] they have to be kind of binary.

00:47:33

Like you don't refer someone to Hospice halfway or you don't stop chemotherapy halfway. Or I take that back, you know, I get asked that people do do that. They'll go, okay I'm going to give you just like a quarter of

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a dose, let's see if this does anything and, one could argue that that shouldn't be done and those are practices that really there's no evidence base behind it, but people find their way to try to do things halfway like that.

00:48:02 But for the most part these decisions are pretty binary and that's just the nature of decision making in healthcare. So, we need to draw some [inaud.] line, we need to figure out these [inaud.] points and then to sort of position decisions around them and yet that line doesn't exist in nature. We'll that's something that we negotiate and construct with our patients.

00:48:25 We kind of figure out when is the right time to do, you know, to refer you to Hospice or whatever or to stop chemotherapy. So, in some ways even if we go to the rectangle that you're proposing, which I agree with, which is more evenly distributed, we still have that problem of when is the right [inaud.] point.

00:48:44 You know, when do we make these certain binary decisions, and to me that problem remains and I don't

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know, you know, how - what is the best strategy to do that, but I'm just raising the question of whether we can get better at that and if we understand more of the science behind how do we kind of work with people's optimism and work with uncertainty to get them to a different frame of mind that's more kind of adaptive in some ways.

00:49:23 BILL KLEIN: All right, thanks. And thanks for your great presentation.

00:49:27 DR. PAUL HAN: Thank you, Bill.

00:49:31 DR. JERRY SULS: So one of the things that occurs to me on one hand the idea of trying to create a cognitive reframing that encapsulates, hope for the best, prepare for the worst, seems very daunting to me.

00:49:44 DR. PAUL HAN: Yeah.

00:49:46 DR. JERRY SULS: But on the other hand I have to admit that if one looks at the work that's been done on optimism, both experimental and correlational there

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actually has been a fair amount and Bill has very strongly associated with this of trying to reduce the optimism bias and that hasn't - those attempts in most cases have not been successful, at least it's hard to do that's for sure.

00:50:20 But I have to admit that in actuality research who do work on affect, the optimism bias, and decision science, I'm not sure they've ever actually taken up the [inaud.] of thinking about how you create a reframing where there is some uncertainty and ambiguity but it's greeted with a certain amount of flexibility.

00:50:47 I'm not sure that's actually been something that has been a topic for researchers in a direct way and maybe one of the, I think one of the implications of your comments is that ought to be an aim that people should put that on their agenda, because I'm not sure they really have.

00:51:14 DR. PAUL HAN: Yeah, I mean, you would know this, I don't know this area of research so I defer to your collective wisdom, but I do think that if people

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aren't looking at it, they ought to be from perspective as a clinician. And again, I want to emphasize, I mean what I would argue, again strictly as a clinician now, not as a researcher, but my gut feeling as a clinician is that the goal is not to make, to be bias and get people out of the optimism bias.

00:51:49

As kind of weird as that might sound and maybe inappropriate if you think about healthcare expenditures in this country and overly aggressive care, etcetera, I realize that that's a danger of the optimism bias, and yet at the same time I don't see it, I personally don't see it as the goal to make it go away or as much as I see, as [inaud.] talks about, but also it doesn't hold a concrete proposal, I think that's at least applicable to this domain, how can we not make it go away but make people more aware of it, increase people's awareness of it and somehow work with it.

00:52:28

And maybe redirect it in a way. And that's what I don't - I don't know what that really means or how we would operationalize that, but I actually don't see

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the issue as being one of let's make it go away, let's figure out how to make the optimism bias go away as much as how can we redirect people or how can we increase their self-awareness and then learn how to work with them, you know, together, you know, with this very difficult problem.

00:53:02 DR. JERRY SULS: Do you think that the issue of shifting gears becomes more or less complicated with the addition of family members, relatives, and also with a medical care team that's engaged with the patient?

00:53:20 DR. PAUL HAN: Yeah, it depends on the who.

00:53:24 DR. JERRY SULS: Okay.

00:53:24 DR. PAUL HAN: Because as you saw in those two cases, those were very different clinicians and very different, at least one case family, I've seen it be the case where the family helps, because they see things in a different way, they're able to sort of work with the patient's values, or, you know, reorient the patient.

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00:53:43 I've seen them compound the problem dramatically. I've seen clinicians compound the problem dramatically, as well as make it better. And the second case I showed you there was some interprofessional conflict actually there too, different perspectives from the PCP and an oncologist, and you know, it really depends on the situation and the person. It could really go both ways.

00:54:06 DR. JERRY SULS: Let me ask you one, I guess, final thing. Would it be useful to, and I'm not sure how one would do this exactly, identify medical teams and/or specific physicians for whom this seems to work better. And when I say better, I'm not sure exactly I know what the outcome would be to use to try to figure out exactly what's better, but I wonder whether seeing what certain role models do if they can be identified, might help to get a sense of how to strike the right balance.

00:54:51 DR. PAUL HAN: Yeah, I think that's a great idea, Jerry. I think there are seasoned clinicians out there who have this down, and again my senses, some of

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them do some - a fair amount of writing about this, but I know many don't, you know, they're just good at it, but it would be great if we could kind of [inaud.] best practices and maybe that's a good starting place, and then that way try to get at what are those mechanisms.

00:55:15 But, you know, there's a good deal of writing about this stuff already, but again, I think there's a lot less empirical work on this. There's a lot of, you know, [inaud.] of wisdom out there, but very little of it has been actually empirically tested.

00:55:33 DR. JERRY SULS: Okay. Well, this has been a very interesting and I think important discussion and I appreciate all the comments you made and all your preparation. I think this really does add a new perspective especially to our webinar series on decision making. So, thank you very much.

00:55:56 DR. PAUL HAN: Great, thank you for inviting me.

00:55:58 CHELSEA PROUGH: Thank you Dr. Han for providing today's information. If you have questions after

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