RACIAL AND ETHNIC INEQUITIES IN END-OF-LINE PAIN MANAGEMENT

Rashmi K. Sharma, MD, MHS: It's my pleasure to be able to talk with you today about racial and ethnic inequities in end-of-life pain management, and thinking about strategies to provide high quality, equitable care.

I want to start by reviewing the learning objectives for today's talk. So at the end of this educational activity, participants should be able to characterize the data on racial and ethnic inequities in end-of-life pain management, describe the multilevel barriers that contribute to inequities in end-of-life pain management, and, finally, identify some of the strategies to address racial and ethnic inequities and improve care for patients at the end of life.

Prevalence of Pain at the End of Life

So to start with, I'm going to talk about what we know about the prevalence of pain at the end of life as well as thinking about the context of serious illness more generally to kind of set the stage for why this matters in clinical practice.

And I like to start by showing this slide just because some of these terms, palliative care, hospice, and end of life, can be a little confusing. There's overlap. And, as I go through some of the data that I'm going to present, I'm going to be talking about different combinations of these terms and populations. So palliative care is specialized medical care for patients with serious illness that focuses on quality of life. This model, which kind of originates from the cancer literature so you can see curative care, is still applicable to other types of serious illness. From the time of diagnosis, there's usually a focus first on disease modifying treatments. Palliative care can be provided concurrently and often should be provided at that time, but it will kind of take the back seat to these disease-modifying treatments. Over time, as the disease progresses, there's a shift with that role of palliative care really increasing over time, as you can see in that blue triangle. And then, of course, palliative care and hospice, which I'll define in a second, can be provided through end of life, which is that kind of pink box that you see towards the right side.

Now end of life is not a precisely defined term. It has variable definitions. It often refers to about 12 months prior to death, so that's the time frame that I'm going to use in talking about this topic. And then hospice, which does have a precise definition, is defined by the hospice Medicare benefit and its care that is focused on quality of life in the context of a life-limiting illness for patients with the life expectancy of six months or less. And so you'd see that that would generally fall into this kind of larger, broader definition of end-of-life care. And then, of course, after death, the kind of philosophy of palliative care and hospice support includes bereavement. So, as I mentioned, some of the data that I'm going to be presenting is going to fall under palliative care patient populations, some of it is going to refer the care for patients in the hospice setting, and then some is going to use terminology around end of life.

All right, okay. So let's talk about what diseases are often the focus of care for those at end of life. And here you can see the leading causes of death by age group in the US - this is data from 2019, so prepandemic - and I think, not surprisingly, you can see that heart disease and cancer are the top two causes of death. And then as we look at that older population, particularly those 85 and over, you can see dementia there as the third leading cause of death in the US.

And that really matched to the diagnoses that we see most frequently in the context of hospice care. So here you see primary hospice diagnoses - this is data from 2018 - you can see that cancer is the most common primary diagnosis and accounts for about 30% of hospice primary diagnoses followed by heart disease and then dementia. As you look at that figure, you can also see that over the last few decades, there's been a marked rise in the use of hospice for noncancer diagnoses, again, though, with cancer still being the primary or the largest diagnosis. And then I also want to mention that another trend we've seen over time is the increase in multimorbidity, and so many of these patients, even if they have cancer, for example as their primary life-limiting illness, oftentimes have additional chronic and other life-limiting conditions.

And so here you can see the prevalence of different symptoms now across several of those advanced illnesses that we were just talking about. And since this talk is about pain at the end of life, we'll look at the bright blue column there, that very first bar, that is showing prevalence of pain in these different populations. And the takeaway here is really that a significant number of patients have pain in the setting of advanced illness. You see it's particularly high in the context of cancer, and, indeed, as I go through some of the data, you'll see a fair amount of data is coming from the cancer population.

And an example of that would be in this slide where we're now getting kind of narrowing a little bit more on prevalence of pain for patients with advanced cancer. In this systematic review of studies from around the world, the prevalence of mild, moderate, and severe pain really varied quite a bit by region and setting. However, I think the key point here is in several of these studies you see that more than half of patients had moderate to severe pain. So there's a pretty significant burden of pain in this population.

So given the prevalence of pain, right, so pain is occurring frequently in populations with serious illness; and the intensity of pain that many patients are having moderate to severe pain; and thinking about the impact of pain on all aspects of life, the management of pain, thus, is one of the key domains as we think about high-quality palliative care. You can see that in the second row, right, the physical aspects of care. So in other words, it's really incumbent upon us as clinicians to ensure that we are adequately assessing and treating pain for all patients at the end of life.

Racial and Ethnic Inequities in End-of-Life Care

So now I want to turn to talking about racial and ethnic differences in the context of end-of-life care. I'm going to start a little bit more broad and then I'm going to focus in a little bit more on the area of pain management. And I want to mention, you know, a couple of things up front. So the first here is that race is a social construct, right, so there are no biological human races, but people do live the experience of race. And so it's important to think about how that role of race translates into the type of health and healthcare that people are experiencing.

And I think this should not come as a surprise to people in this audience as we think about kind of why are we talking about racial and ethnic differences, why does it matter? I'd say that over these last two years, particularly in the context of the COVID-19 pandemic, there's really been growing recognition of how important, I would say, kind of need and urgency to address racial and ethnic inequities in healthcare.

In this figure, I just want to highlight that the racial and ethnic makeup of the US population has been changing, right, over the last couple of decades. Again, I don't think this is a surprise to anyone in this audience. And you can see that even as we go forward-looking at projections which indicate by 2045 that a greater number of Americans will identify as being from one of these racially or ethnically minoritized groups, right, so the minority will make up more than half of the population in the US, right. So there's really a practical need for us to understand what are the drivers of racial and ethnic inequities in care, and to develop solutions so that, for this growing population, we can ensure that they also have optimal access to good quality healthcare and the chance to have good quality care at the end of life as well.

In addition to the fact that the demographics are, of course, changing within the US, the other key reason why we're talking about racial and ethnic inequities is that we see so many of those. We see those across different kinds of clinical outcomes and illnesses. And here, in this figure here, you can see that Blacks with cancer are at the highest risk of death compared to other groups with cancer. This risk reflects delays in diagnosis. It reflects delays in treatment, which are due to a combination of factors; and I'll talk more about issues like structural racism and social determinants of health and healthcare disparities, some of the reasons why we see these differences, but it's just to highlight that these inequities are having really significant effects on populations such as those who identify as Black in the US.

So we see inequities across a wide spectrum of illnesses and areas within healthcare. And as this talk is focused on end of life, I'm going to go over some of the data that we see in respect to end-of-life care. So on this slide, you're seeing that a higher proportion of Black and Latino Americans die in the hospital compared to White, that fewer die in nursing facilities or in hospice. So we see here that racial and ethnic differences exist in terms of place of death when we're thinking about the population with serious illness and those who are at the end of life.

Data from that same study also shows a significantly higher use of intensive treatment at the end of life, so here again, you're seeing that Black and Latino patients are far more likely to use life support or life-prolonging treatments at the end of life. They're more likely to use dialysis before death as well.

And that trend continues in other studies as well. So here in this study that was looking at a cohort of patients at risk for stroke, we see that Blacks are more likely than whites to be hospitalized. Within the last six months of life, they're also more likely to undergo procedures, so, again, as a measure of kind of treatment intensity. In this particular study, you don't see significant differences between Blacks and Whites in cancer whereas you do in CBD, in dementia, and in other illnesses. I will say that there's other data, though, that does indeed show the same trend of higher treatment intensity and decreased use of hospice among Black Americans at the end of life.

And so here, one more example in the context of advanced dementia, where you have Blacks being more likely to receive mechanical ventilation at the end of life. But on that figure on the right, you see that mortality differences don't exist between Blacks and Whites in this cohort and mortality is really quite high, right. What does that mean? That means that, despite the use of this high-intensity care at the end of life, that's not really translating into significantly improved mortality. And I would say, in contrast, there's other data that shows that for patients who are receiving high-intensity end-of-life care, that that's actually associated with poor quality of life and associated with higher psychological distress for caregivers.

So while these differences that I'm showing you might reflect differences in preferences, right, so it's possible that in this case, for example, Blacks are more likely to receive mechanical ventilation because that is their preference, right, they're preferring to receive high-intensity or life-prolonging treatments even in the context of advanced dementia. However, I think it's important to make the point that some of these differences may also reflect inequities in care. So, for example, it may be that poor quality or even absent communication about goals of care, or a lack of trust in the healthcare system from past experiences, may lead patients to pursue higher intensity care. So there may be other factors that are actually underlying what we see as preferences, so that may be explaining some of these patterns of care.

And one of the things I'll talk about a little bit more further on in this talk are some of those specific drivers of inequities that may be contributing to these patterns that we are seeing. But I think the main takeaway from these few slides is that we do see a pretty consistent pattern of higher intensity end-of-life care for, I would say, all racially and ethnically minoritized groups, but here we're really focusing on the differences that we see for Blacks. So we're seeing that pattern, and the worry is that that pattern may reflect, as I said, poor quality of life and higher levels of psychological distress.

Racial and Ethnic Inequities in Assessment and Management of Pain

So I think that's some of the broader context for what we see as we look at end-of-life care more generally and now, of course, I want to narrow in on what does the data show when we think about how well we're managing patients pain at the end of life. And I'll give away the main thing that you're going to see, which is the data is really mixed, and so I think this is actually quite a complicated question to tease apart in terms of what are we actually seeing here?

So I'm going to start out with data from these two studies, which looked at racial and ethnic differences in pain in the context of palliative care consultation. On the left here, you can see that in this sample of patients who had a pretty poor functional status, you see that as evidenced by the palliative performance scale, the proportion of Black patients with any pain, as well as the proportion with moderate and severe pain, was higher than it was for Whites, but these differences didn't reach statistical significance.

On the figure on the right, you can see that pain for all groups of patients decreased following palliative care consultation. So it was really quite high at baseline, again, another reminder that this is an important quality measure as we're seeing significant amounts of pain for these populations. So palliative care consultation seemed to help at least improve the pain that patients were experiencing, but we didn't see any racial differences in this study in pain severity, either at baseline or at 24 hours following a palliative care consultation. Now the authors here did find that, at the time of hospital discharge, Latino patients had a higher risk of having more severe pain compared to Whites. And again in this study, they didn't find significant differences between pain intensity between Blacks and Whites.

Now in this study, which was looking at older adults in the hospice setting, we see that Black patients had a lower odds of receiving a pain assessment on admission to hospice. The authors actually found the same was true for the final assessment, the final pain assessment prior to death or hospital, sorry, hospice discharge. Now when pain was assessed, though, there were no racial differences in the use of a valid pain assessment tool, right. So, in other words, the difference here was between whether or not patients had their pain assessed. If they did, it was equally likely that a standardized tool would be used to assess that pain.

In this study, the authors did also, though, find that Hispanic patients had a lower odds of receiving opioids compared to Whites. Again, in this study, they didn't find a significant difference in the odds of receiving opioids for Blacks compared to Whites. They also didn't find any racial or ethnic differences in the receipt of nonpharmacologic treatments.

In contrast, in this study, which also looked at older adults enrolled in hospice but used a newer data set, so this is looking at those that were enrolled between 2014 to 2016, here, the authors did indeed find that Black, Hispanic, and other race patients were significantly less likely to be prescribed opioids for their pain. And you can see that reflected in these adjusted odds ratios; so that's even after adjusting for other characteristics or potential confounders.

So I want to turn from older adults in the hospice setting to looking at patients with advanced lung cancer and looking at the context of kind of over the course of end of life. So here, on the left, as you might expect, you see that a higher percentage of patients received pain medications in the last month of life, so that's the End of Life-1 period that's indicated there, labeled there. On the table, data from the last month of life shows that Black, Hispanic, and Asian patients were all less likely to receive any pain medication. So, again, we're seeing this pattern where it's towards that kind of like last stage of end of life that you really see this increase in receipt of pain medications, in general, whether that's reflecting increasing level of pain in patients with advanced cancer and/or to what extent that's reflecting clinicians be more likely to prescribe opioids; it's probably a combination of those two. But despite that overall trend of higher pain medication use, we still see that all of these racial and ethnic minority groups are less likely to receive pain medications in that last month of life.

So in this study of patients with brain metastases, we see different findings again, right, so here only Asian patients were less likely than whites to receive opioids, and there weren't any statistically significant differences in nonopioid pain medications across any of these groups. So here, again, in contrast with the previous study, these authors didn't find that Hispanic or African-American patients were less likely to receive opioids. So, you know, this leads to kind of a confusing picture. We're seeing that some studies are, indeed, documenting inequities for some groups and some are not. And that was the takeaway from a recent systematic review, which summarized that there wasn't any kind of clear consensus about what was going on in terms of inequities in the treatment of serious illness pain. But I think there are a couple of important takeaways. And so the first being that there are, indeed, some segments of the population in some context that are experiencing inequities in the assessment and the management of pain, particularly when it comes to the use of opioid medications.

I think the second point that's worth noting is, you know, some of the weaknesses of some of these studies, which are that many of these studies used secondary data sets and didn't include patient-reported measures, so we don't really have a good sense of the severity of pain that patients were having and the extent to which that pain was well managed. So in this study, for example, we're just looking at whether or not patients were prescribed opioids, right, but we don't have details around the dosing of those opioids and the efficacy of those pain medications. So I think the important point here is that there's still a lot that we don't know about the potential inequities for this population, that we see some indications, as I mentioned, that some people are indeed experiencing inequitable management of end-of-life pain, and then as I'm going to go through in the next section, I think there are a lot of reasons to think that there are likely drivers of some part of inequities in this context for these patients at the end of life and opportunities for us to do a better job of providing high-quality pain care.

Drivers of Racial and Ethnic Inequities in End-of-Life Care

Okay, so let's talk now about some of these drivers of racial and ethnic inequities, particularly in the context of end-of-life care.

So when we think about health inequities, in general, there are really three main causes. The first are structural inequities. These are structures that organize the distribution of power and resources differently across lines of race, gender, class, sexual orientation, gender expression, etc. Then we have social determinants of health, an example of which you can see here in this figure. And then, finally, there are healthcare disparities, and these reflect both clinician behavior as well as system level factors. In the context of healthcare, we're talking about healthcare systems.

In addition, we see that barriers to equitable health can occur at multiple levels. There's the individual patient and family level, there's the clinical encounter that reflects both the clinician factors as well as the visit that's happening between the patient, family, and the clinician, the healthcare system, and the community or societal levels as well, right. So there are multiple levels at which these different inequities occur.

And I'm going to use this framework as a way to think about how do we integrate those different multilevel factors and explain how these factors then translate to equitable or inequitable outcomes in the context of serious illness care and thinking about the end of life?

So on the left here, you see the multilevel barriers that affect end-of-life care that a patient receives, right. You can see some of the barriers that occur at the individual level, and you can see some of the barriers that occur at a health system or community/societal level, right, things like the structural and financial barriers that patients experience as well as things like structural racism and historical discriminatory practices against different groups of people. So we have some of those multilevel barriers there in that gray box.

Then we have the healthcare mediator, so this is also then reflecting that clinical encounter barrier that I just showed you on the previous slide. And these healthcare mediators can either facilitate equitable care or they can perpetuate or serve as additional barriers to equitable care. So those are the healthcare mediators in the green.

And then you have the model of care as it relates to end-of-life care, so that could mean access to palliative care or use of hospice, acute medical care. It also reflects the intensity of the care that's provided and the duration of care that's provided.

And so together those multilevel barriers with the healthcare mediators that can either facilitate equitable care or serve as a barrier to equitable care, in addition to these models of care, that translates to the clinical outcomes that are of relevance for patients at the end of life. And so here we're talking about things like quality of life, symptom burden - of course, this presentation is focused on pain - as well as patient satisfaction of care and receipt of care that is aligned with their values and goals. So I think this is a helpful framework for thinking about the role of these different multilevel barriers and how at the end of the day they can translate into equitable or inequitable pain management at the end of life.

So I'm going to go through now some of these individual kind of level barriers. So in this study, you can see results or data from patient-reported barriers in a sample of Black patients with cancer. And the majority of barriers here cited were those that participants agreed related to concerns about addiction, side effects and dependency. You can see some that reflected the interaction with the clinician, right, like it's more important for the doctor to focus on curing illness and to put time into controlling pain. You can see worries reflective of having more pain means the disease is getting worse, so thinking about the trajectory. But I would say that concerns about addiction, side effects, and dependency really stand out as some of the big barriers identified from the perspectives of Black patients with cancer.

And here some of the same concerns come through in a different study that looked at Black and Hispanic patients with cancer pain. And you, again, see some of the same trends in terms of concerns about tolerance or addiction, worried that the pain medicine won't work, concern about side effects. So those are commonly reported, right, by both of these groups . And then you see some kind of more subtle differences. For example, 65% of Hispanic patients compared to 36% of African-American patients had concerns about family member reactions to their use of pain meds, so that concern being something that was more prevalent among the Hispanic patients interviewed in this study. Whereas 77% of African-American patients wondered why the doctor hasn't assessed their pain compared to 36% of Hispanics, right. So again, there are some, I think, nuances in terms of specific concerns that may be more prevalent for certain groups, but you'll also see a lot of the overlap that is happening here. So that's one way to look at some of the barriers that are occurring at the individual level. And again, this is coming from the perspective of the patients themselves.

So a separate issue, as we think, again, about the different levels of care, relates more to the system and structural barriers that I talked about thinking about kind of community and society. And so here's data from a study in Michigan that was looking at availability of opioids and disparities in terms of pharmacies that had sufficient supply of pain medication, specifically opioids.

In the top here, you can see some of the differences as they looked at pharmacies that were located in minority predominant zip codes compared to pharmacies that were located in White zip codes. And in the bottom here, you see pretty striking differences that even after adjusting for pharmacy type, median zip code age, which was a difference that was highlighted up above, and the presence of a hospital in the pharmacy zip code, pharmacies in white zip codes were still much more likely to have sufficient opioid supply than pharmacies that were located in minority zip codes. And this disparity is really striking in lower mean zip code areas, right. So in areas with lower income, you see that pharmacies in White zip codes had a 54 times higher odds of stocking opioids than those in minority zip codes. And so, you know, these data really highlighting that aside from kind of what we've been focusing on, which are more patient- and clinician-driven barriers to high-quality pain management, that issues such as is the pharmacy that's near your home sufficiently stocked so that as a patient you can get the medications you need, these are some of the larger barriers that can really drive inequities in care.

So reflecting then a little bit more on these different levels, you know, so, again, in those earlier slides showing data about some of the fears and concerns that were expressed by patients and so this is kind of summarizing some of that data as well as data from a systematic review that was published earlier this year. So we see that concerns about side effects one of the primary concerns when it comes to pain management, and that's something that has been documented as a common barrier to pain management across all racial and ethnic groups.

Another big fear and concern, though, is around tolerance and dependency, and as, at least per Clarke et al.'s findings from this systematic review, that this might be a concern that might be possibly greater among some of the racial and ethnic minority groups. Again, we did indeed see this cited as one of the common barriers in those two studies that we're looking at Black patients with cancer and then Black and Hispanic patients with cancer.

Similarly, this idea of wanting to be strong, wanting to be self-reliant, not having to depend on medications to cope with pain as being a commonly reported barrier to pain management, misconceptions about pain management. I think in the context of end of life, a common misconception is around morphine. There's a lot of stigma associated with morphine and concerns about that hastening death and so misconceptions, as well as just needing more information, right, more information about side effects, what to expect, how medications work. So thinking about unmet information needs as a barrier to pain management.

One of the additional barriers reported hesitancy to report pain unless it's severe, so this kind of idea of stoicism. And, actually, in the study that I had showed that was based on Black and Hispanic patients with cancer, so more than 80% of those patients said they would only tell their physician about pain if their pain was a 10 out of 10. So, you know, really waiting until the pain is so bad before bringing it to the attention of the provider.

And then the other theme that came through from the systematic review was wanting a more individualized approach to pain management and not just thinking about, you know, purely based on guidelines. And I think you know that likely reflects from the patients' perspective again that they're thinking about their full-lived experience and that full-lived experience is going to also reflect some of those social determinants of care, their prior experiences with the healthcare setting, and so patients really wanting their whole self to be seen in that interaction with the clinician and wanting to feel like the pain management plan is going to meet their needs, reflect what's important to them and not just something that is coming out of a book, so to say.

And then as we reflect on the clinician and system and societal level barriers for the clinical encounter level looking at the role of communication barriers. So, for example, for those with limited English proficiency, who often experience care in the absence of an interpreter, thinking about those with low literacy, right, these are populations who are at higher risk to not understand the pain management plan, to not feel empowered to ask questions or to express their fears and concerns, so thinking about how some of those barriers to effective communication can lead to suboptimal pain management at the clinician level.

In addition, thinking about the inconsistent or limited use of pain assessments skills, again, you know, calling back to that study earlier on that showed that Black patients in hospice were less likely to have their pain assessed around hospice admission time. So, you know, in order to adequately manage someone's pain, you need to be able to assess it, right, and so that being an important clinical encounter level barrier.

And then implicit bias, which translates into the hesitancy to prescribe opioids, right, like a bunch of those studies that we're looking at differences in receipt of opioids. Think one of the hypotheses there is that providers are maybe less likely to prescribe opioids to Black patients and also to wait until patients are near the end of life before prescribing opioids in particular.

As we think about the healthcare system, again, so there is the clinician's role in assessing pain and then there are interventions that can be placed at a system level to ensure that patients have their pain routinely assessed and so the lack of those interventions being an important healthcare system level barrier. And then, you know, multiple barriers for patients as they try to navigate the healthcare system just thinking about the number of steps that they need to go through in order to get a refill, for example, of their medication, particularly if it's an opioid medication. So thinking about the barriers that exist as patients have to navigate that system even if their provider has, you know, assessed their pain appropriately and come up with a treatment plan.

And then as we think about kind of the broader level thinking about the way in which barriers to access to healthcare can drive inequities for this population at the end of life, thinking about the cost of treatment, I'll say a little bit more about that again in a few slides, but, you know, financial toxicity being something that is being talked about a lot more now, particularly in the context of serious illnesses like cancer, so thinking about how that can really serve as a barrier to patients being able to fill their medications or access healthcare.

And then as I was just showing in that previous slide, again, back to thinking about kind of the structural barriers to health equity thinking about those disparities that we saw in the stock and supply of opioids at local pharmacies based on where they're geographically located.

Addressing Racial and Ethnic Inequities in EOL Pain Management

Okay, so, hopefully that gives us a sense of what are some of the drivers of inequities as we think about this patient population. And so this section is really going to try to kind of map to that multilevel approach and talk about how we can develop interventions and strategies to provide high-quality, equitable care to patients at the end of life and ensure that we are providing optimal pain management.

So the first thing I want to mention here is it's really important to recognize that there are multiple dimensions of pain in the context of end of life. These are just two models that highlight some of the different ways to think about these different dimensions. I think, importantly, as you look at both of these models, you can see the way in which factors such as social determinants of health, structural racism, healthcare disparities can directly contribute to several of these domains. And so I think it's really important, as we think about how to manage people's pain, that we recognize that there are multiple drivers of what's contributing to that pain and so, thus, there may be different solutions and different considerations as we try to unpack what is driving their total pain that patients are experiencing and reporting.

So I want you to keep that multidimensional model of pain in mind and then think about, as step one to providing equitable pain management, it's conducting a comprehensive assessment of all of these dimensions of pain. And so as one key part of that, again, reflecting on some of the data that we had about Black patients not receiving assessment of their pain as routinely as well as their own reported concerns about the doctor not asking them about their pain. So, you know, number one here, use standardized tools to assess the pain, both physical pain as well as total pain. And there are many ways to do this from, you know, numeric rating scales, visual analog scales. There are behavioral scales for patients who can't rate their pain, but it's really important to routinely assess, as in in every clinical encounter with the patient, be assessing their pain.

And then, as a second step, you know, really thinking about cultural humility as an approach to understand the sociocultural, psychological, and spiritual aspects of their pain, right. Again, on this previous slide, the different dimensions of pain, being able to really, as I said, kind of unpack what is going on here and what is driving the pain so that we can come up with strategies to intervene.

As part of that, it's thinking about the ways in which structural racism; past experiences with healthcare, particularly if those experiences didn't go well; a lack of trust in institutions; challenges with, you know, access to care, which may be driving anxiety, how all of those factors could be contributing to the different dimensions of pain that the patient is experiencing.

And then next, it's really thinking about, okay, now that you understand the different dimensions of pain that this patient is experiencing and the different factors that might be contributing to that pain, then really thinking about how to individualize the pain management plan, again, reminding you of the findings from the systematic review where one of the patient-reported barriers was feeling like clinicians were just using guidelines and not really thinking about the pain management plan for like this unique individual, so really, again, keeping that kind of patient-centered approach in mind.

And then I didn't really talk about, you know, actual approaches to treating pain, which is another topic, but thinking about both pharmacologic and nonpharmacologic treatments. Again, I'm really harping on this multidimension piece but, you know, thinking that there may be a combination of modalities that can treat the different components of the pain that this patient is experiencing in the context of end of life.

And then really explicitly exploring and addressing patient and family caregiver fears and concerns about management options, again, thinking about things like side effects and dependency which were some of the more commonly cited concerns, being able to understand any misconceptions that they might have about pain management and any gaps in understanding. So in the same way I would say from a palliative care approach that it's really critical to assess patients' understanding of their illness, in the same way, it's really critical to understand, to assess patients' understanding of the pain management plan so that you can identify gaps, correct those gaps, provide more information, and help facilitate a plan that everyone is going to support and be on board for.

And then as we think about addressing some of these clinical and system level barriers, again, we have this use of standardized pain assessments for physical pain to do these assessments routinely. I'm kind of harping on this point because I think this is one of the easier to implement strategies for addressing barriers is to be able to do this. So, again, thinking about, for example, at hospice admission time, that there should be a standardized practice where all patients have their pain assessed at the time of admission.

I think I would argue that there's a role for the need to educate clinicians about palliative care, which can be one strategy to help improve the quality of end-of-life care and really think about moving palliative care upstream, again, thinking about some of that data where we see delays in treating patients' pain until you know, kind of very at the end of life, so thinking about how palliative care could help be a mechanism to address that barrier. Thinking about implicit bias training, educating clinicians to address misconceptions they might have about racial differences in pain and suffering.

And then really leading clinical interactions with respect. I mean I think you could argue that that's a cornerstone of all clinical care is to be able to lead those interactions with respect. But I would just point out that when it comes to the context of end of life, you have patients who are often at their most vulnerable; and being able to really show respect in that moment is fundamental to being able to build a trusting relationship where together you're going to navigate some of these really difficult, sensitive topics, you know, kind of challenging issues. Respect is especially paramount in these interactions. And so that can be as simple as starting the interaction by addressing patients by their surname, right, asking patients what name they want to be preferred to be called by but at least showing these signs of respect at the beginning of your interaction with patients. Asking permission before doing a physical examination, right, or asking permission before asking some difficult or tough questions or sensitive questions. So, you know, again, I think this is another example of, I think, an intervention that is easier to implement then some of the other ones I'll talk about in a moment, but you know, again just really leading clinical interactions with respect, thinking about cultural humility, thinking about curiosity, right, really trying to understand what's driving the patients' concerns or what they're bringing to that clinical visit.

And kind of along those lines really thinking about good patient- and family-centered communication practices, so explaining information clearly. Then in the context of low literacy, thinking about how you might need to simplify information; in the context of limited English proficiency, thinking about using medical interpreters; and for everyone else, again, you know, really thinking about how to communicate information in as simple a way as possible, repeating information as often as needed to ensure understanding. I mean there are some studies showing that patients retain only about 10% of what's being said, especially if they're in a situation where they're being overloaded with information or in kind of a high emotional state. And so, again, as we think about serious illness, almost all of our conversations are like that and so it's not surprising that even if you thought you've done a great job explaining how this opioid works or why this might be helpful to the patient, recognizing that that might not have really registered and that you might need to kind of go over the same information multiple times; but, you know, again, really checking in to ensure that the patient and their family are understanding the plan.

Using trauma-informed care approaches. As I had just mentioned on the previous slide, patients at the end of life are in a really vulnerable place, and oftentimes some of the traumas that people have experienced during the course of their life really manifest at this time. They're scared, they're distressed, they're anxious, and so those traumas can really kind of play into that distress and anxiety and fear and pain, actual experience of pain. And so, you know, being able to think about then some of these trauma-informed care approaches to help navigate and understand where people are coming from is particularly helpful.

And then clarifying values and goals. So, you know, again, I think that's fundamental when we're thinking about end-of-life care, in general, but it's for sure relevant; as we're thinking about pain management as well, it's understanding what's important to people. I really like this question just as an example, you know, "No one decision is right for everyone, as you think about your options, what's important to you?" And I would say, as an example of where I think values and goals are really relevant to the management of pain, thinking about the balance of side effects, right. I would say that a frequent issue that comes up is thinking about the wanting to be alert, but maybe that means having a little bit more pain versus having better control of pain, but maybe that means being a little bit more sedated again in the context of end of life and thinking how that's really, at the end of the day, about what's important to that patient in that moment, right. Maybe they really want to be alert because family is coming, and they want to be able to spend time with their family even though their pain is not going to be as well controlled. And the converse may be true as well.

And so the only way to figure out how to provide good-quality pain management in that setting that meets the patients' needs is to understand what their values and goals are and what's important to them, so, you know, always having that piece in the back of your mind about, you know, making sure that there's clarity about what's important to the patient and their family. And that can really even help guide the pain management plan, which may change, you know, particularly as they get to the very end of life.

And then, you know, thinking about these broader issues around the barriers that occur at a societal level, at a community level, you know, I would say I think these are definitely the barriers that are a little harder to implement or to address as an individual, but I want to call out these because they're important. So thinking about policy and payment reform, right, we need to really be thinking about how to improve health insurance coverage, thinking about programs like Medicaid expansion to ensure that patients actually have access to healthcare so that they can receive optimal end-of-life pain management, thinking about things like decreasing cost sharing for high-value services such as palliative care, I think could be a way to really help patients who are navigating serious illness.

Again, these are, you know, I think the things that need to be done and are hard to do. Things like addressing structural racism and its role in the inequitable distribution of opioids to local pharmacies, thinking, again, about kind of structural racism's role in driving financial toxicity, right. So here we can think about social determinants of health policies like, you know, redlining and things like that that make it harder for people to gain financial stability. And in the case of illnesses like cancer, the expenses are so considerable that many patients are dealing with financial distress and the ways in which that can act as barriers to them receiving medications, filling medications, as well as likely driving some of those other multidimension aspects of their pain. So there are multiple tools out there that can at least enable the screening of needs for a particular patient to identify that, oh, this is an issue and then thinking about interventions that can help.

Again, this is pretty general, but it's important to think about diversifying our healthcare workforce to benefit and address some of these inequities in care.

And then, finally, I just want to really point out that there's a need to support research that engages minoritized communities, thinking about ways to better have systematic collection of race and ethnicity data for people with serious illness. I mean one of the limitations I think from this talk is that there is no clear consensus on the extent to which there are racial and ethnic inequities in end-of-life pain management and part of that reflects a need for there to be more research. And more research requires a systematic collection, so things like race and ethnicity I think with the pandemic we've made some progress at a national level in thinking about better ways to do this, but there's still a need to better understand the experience of pain at the end of life and thinking about the ways in which Black patients, in particular, may be experiencing poor quality care.

Summary Points

So that takes me to my summary points here for this talk. So here are the things I really want you to take away from this talk. Number one is that pain is one of the most common symptoms for patients with serious illness and at the end of life and that many patients experience moderate to severe pain. So it's frequent, it's common, and it can be quite high intensity.

Assessment and management of pain is an essential component of high-quality palliative and end-of-life care. So, again, it's frequent, it's common, it can be high intensity. We really need to do something about it and ensure that we're treating pain adequately.

Racial and ethnic differences occur in multiple domains of end-of-life care. We see that in terms of where people die, the kind of intensity of care that they get at the end of life and that these differences likely reflect some of the inequities that occur at the patient/family, clinical encounter, healthcare system, and community/societal levels.

And that there's mixed data about the extent of racial and ethnic inequities in assessment and treatment of end-of-life pain but, clearly, certain populations do experience inequitable care. And I think there are a lot of reasons, as we think about these broader racial drivers of racial and ethnic inequities, to believe that there are, indeed, inequities that are occurring in the context of pain management. And so really what we need are multilevel interventions to address some of these drivers of inequities and thinking about some of the key strategies in the context of end-of-life pain management. It's thinking about standardizing pain assessment, improving patient- and family-centered communication, right, so really understanding people's fears and concerns, and thinking about those individual level barriers to high-quality pain management, addressing clinician implicit bias so that's where we're thinking about ways to intervene on how bias might be leading to delayed treatment or decreased use of opioids, for example. And then, of course, thinking about policy reform so that we can address some of the ways in which structural racism and social determinants of health are contributing to inequities at the end of life and thinking about how we can improve access to healthcare, equitable distribution of pain medications, access to opioids for pain at the end of life, in addition to thinking about nonpharmacologic treatments as well.

So, on that note, just want to thank you for your attention to this talk.

END OF PRESENTATION