

[MUSIC PLAYING]

**SPEAKER 1:**

So I'm going to start out by talking about trying to define high quality care. I think we hear the phrase quality care all the time, but what does it really mean?

So a few years ago I was in Boston and I heard a talk given by Lowell Schnipper about quality of care, and I took away from his talk what I thought were the four key tenets of quality care. So the first is to achieve optimal clinical goals for all patients. The second is to use the right amount of care, avoiding underuse or overuse of care. The third is to engage in shared decision-making between clinicians and provider-- clinicians and patients, and the fourth is to manage our resources responsibly.

It all looks pretty good on the slide, right? It seems easy, we should be able to do this, but I think everybody in the room knows that the actual day-to-day delivery of quality care is incredibly complex. And in fact, unfortunately, we know that there are disparities in the quality of health care. There's a body of literature that shows suboptimal cancer care and outcomes across cancer types, and we've seen studies that show support for variation in delivery of optimal care across regions, across health systems, across practices, across individual providers, and across patient populations. So in order to reduce these variations and improve the quality of care that we deliver, we need to understand the factors that are involved in the delivery of high-quality care and the interplay of those factors.

My mentors and I have based our work on the classic conceptual framework that was published in 1999 by Mandelblatt and colleagues that describe the factors that are involved in the delivery of high quality of care. The outcomes in this concept are-- you can see at the bottom Outcomes of Care or high quality care, and they include patient satisfaction, patient functioning and quality of life, both disease-free and overall survival, the cost of care, and the personal financial burden experienced by the patient. And I think we can probably all agree that these do all contribute to high quality care.

The model takes into effect patients and populations on the left-hand side, and providers on the right-hand side, and you can see that central to the model is communication between patients and providers, but patients and providers don't exist in a vacuum. They exist within a broader context. Patients exist within their individual context, which you can see in that circle

on the left, and we as providers exist within the context of the medical care environment or the health system.

You can see there are numerous factors listed under both patient and providers that can contribute to high quality care. For patients, things like sociodemographics, the social class, access to insurance, the patient's knowledge, attitudes, and beliefs about health and health care, and their culture and language. For providers, the age and gender of the provider, the training of the provider, the provider's knowledge, attitudes, and beliefs, their perceived constraints, and their sociocultural competence.

Where I'd like to start out is talking about the health care system and telling you about some work I've done looking at factors in the health care system that can relate to quality of colorectal cancer care. I'll then move into talking about patient-related factors, moving over to the left-hand side of the model, and I'll finish the talk by telling you about future work that looks at the individual context in which the patient exists, particularly their partners and how that relates to the quality of colorectal cancer care.

So I'm going to start out by talking to you about studies that I've done looking at the effective care setting in the value of colorectal cancer care. So let's start by saying that national expenditures in the US on colorectal care exceeded \$14 billion in 2010. Colorectal cancer is the second most expensive cancer in the US behind only breast cancer expenditures, and because of these high and rising costs of care it's essential to deliver high value care, which is defined as care that maximizes patient outcomes while containing the cumulative cost of care.

And we hypothesized that where patients received their cancer care, specifically the teaching status of the hospital where patients received their cancer care, might impact the value of the care that patients receive. I would say that it's been the conventional wisdom that academic medical centers may produce better outcomes in patients, but at much higher costs. But in fact if you look at the empirical evidence behind this assumption, it's really quite mixed.

There are some conditions for example, surgery, for colorectal cancer and other cancer surgeries for which there is a clear body of evidence showing improved outcomes at academic medical centers. But there are other conditions, things like pneumonia and heart failure, for which there's been no difference in outcomes shown between academic and nonacademic medical centers. And so we wanted to explore this further in colon cancer care because it is a complex multi-disciplinary disease that involves complex treatment.

So what we did was conduct a retrospective cohort study of patients with Stage 2, 3, and 4 colon cancer. We use SEER-Medicare as our data source, these are patients who were diagnosed between January 2000 and December 2005, and then we followed out their claims data through December 2007. The outcome variables in our study were overall survival, and also the patient's 12-month cost of care. And I just want to point out that we measured the cost of care in terms of Medicare payments, so these are payments that Medicare made for inpatient and outpatient care. We did not take out-of-pocket costs into consideration in this study.

So first I'm going to show you our outcome of overall survival. So we constructed Kaplan-Meier curves looking at overall survival for patients, stratified by stage, and I just want to make a brief note about the treatment of colon cancer by stage. So patients with Stage 2 and Stage 3 disease get surgical resection of their cancer, that's the first step of their treatment, and then all high-risk Stage 2 patients, and patients with Stage 3 disease should receive six months of adjuvant chemotherapy to reduce the risk of recurrent colon cancer. These are guideline-based standard treatment approaches, so this is a very standardized approach to treatment.

It's a little bit different story for patients who have metastatic colon cancer where treatment can be very individualized. Colon cancer is one of the unique solid tumors in that we still have the chance of curing recurrent metastatic disease, for example, if we can resect liver metastases or lung metastases or provide targeted radiation therapy given in combination with chemotherapy. And so there are many different treatment pathways that patients can go through with metastatic colon cancer. So this is not so much an algorithm or guideline-based situation when we're talking about treatment, and I think that's important when I show you the results.

So if you look on the upper left, you can see that overall survival for Stage 2 colon cancer did not vary based on the academic status of the treating hospital, and the same was true was true for patients with Stage 3 disease. No difference in overall survival. If you look at patients with Stage 4 disease, you can see that there is a small but statistically significant variance in those survival curves. So we found that patients with metastatic colon cancer who were treated at academic medical centers had a median overall survival of 16 months versus 14 months for patients treated at nonacademic medical centers.

Now I'll admit that's a pretty modest difference in survival, but I'll also say that one of the limitations of this study is that because we used SEER-Medicare data, we were limited to older

patients, patients who were 66 and older. And I would argue that if you were to do the same analysis in younger patients with metastatic disease, who perhaps are more likely to undergo aggressive curative-intent treatments, you might see an even greater gap in survival benefit for patients who were treated at multi-disciplinary academic medical centers.

So next I'm going to show you the cost, and this is a busy slide and that's OK, I don't need you to look at the numbers. I'll tell you what we did is we estimated a quantile regression model to look at the 12-month cost of care. And we looked at both the mean and median cost of care, but we also looked at the cost of care across the entire continuum of cost so that we were able to measure cost of care for the patients with very low costs all the way up to the patients with very high cost of care. And what we found for patients with Stage 2 and Stage 3 disease was that across that entire continuum of costs, there were no significant differences in cost based on the academic center of the treating hospital. So for Stage 2 and Stage 3 disease, no difference in overall survival based on where you were treated, and more importantly, no difference in cost based on where you were treated.

When we looked at our patients with Stage 4 disease and did that same cost analysis, we found that there was a significant increase in the mean cost of care for patients who were treated at academic medical centers. Their care was about \$8,500 more than patients treated at nonacademic medical centers. But when we looked across that continuum of cost, we found that that difference in mean costs was skewed by a very small number of very expensive patients, so it was only the patients in the 99.9th percentile of cost who had higher costs at academic medical centers versus nonacademic. These were patients whose costs were in the million-dollar range for one year of costs. So across the entire rest of the continuum of care, no difference in cost based on academic status of the treating hospital.

So again, for patients with Stage 4 disease, we found modest but significant improvement in overall survival with essentially no difference in cost when they were treated at academic medical centers. Some limitations of the studies that there were possible and measured differences between patients treated in academic versus nonacademic medical centers, things that we tried to adjust for but just can't measure in claims data, like the patient's functional status or their access to clinical trials and other things that you might be able to think of.

Additionally, we assigned patients to a treating hospital using their primary medical oncologist as an intermediary because you can't, in claims data, get from the chemotherapy where the chemotherapy was given reliably. So we had to use this intermediary method and not all

patients were able to be assigned that way. And finally, as I suggested before, the study only included patients who were older than 66, and I really think that if you did the study looking in younger patients, you might see an even bigger effect in terms of differences in value of care.

So in the implication of this work, I think the first thing is that not all patients can be treated in academic medical centers, and not all patients should be treated at academic medical centers. Only about 25% of the patients in our study across stages received their care from an academic medical center, and that's probably OK for a lot of patients. I think it's the advent of guidelines for example, the NCCN guidelines and the ASCO guidelines that's leveled the playing field for many patients. So for our patients with Stage 2 and Stage 3 disease for whom care has been standardized and there are clear guidelines, I think that they get good value care whether they're treating at nonacademic medical centers or academic medical centers.

But for more complex patients, for our Stage 4 patients for whom there aren't clear guidelines and for whom care is more individualized and may require more innovative and collaborative care, that they may receive higher value care at academic medical centers. And perhaps when we think on a global level about triaging patients and using our resources responsibly, identifying those groups of patients who stand to achieve more value, higher quality care, at academic medical centers, and getting them to those centers for care.

All right, so I'd like to transition, now, away from the systems-level factors, and move into the patient-level factors that can impact quality of care. So the studies I just talked to you about looked at cost of care from the systems level, and what I'd like to do next is tell you about a series of studies that my mentors and I have conducted looking at the cost of care from the patient perspective.

Because one of the things I've realized in my clinical practice is that there are so many aspects of the patient's experience of care that we just can't capture from claims data. Claims data are extremely valuable and they give an extremely important perspective, particularly into the system-level factors, but it's really only through patient-recorded data that we can get a true understanding of the patient's experience of care, so that's what I'm going to tell you about next.

So I'm going to talk about a series of studies that we've done looking at colorectal cancer and financial toxicity. Financial toxicity is a term that's been in the press a lot recently, and that's a term that was coined a few years ago by Yousuf Zafar, who's a GI oncologist and a health

services researcher at Duke, and what financial toxicity refers to is both the objective financial burden, and the subjective experience of financial distress that is experienced by cancer patients related to their diagnosis and treatment.

We know that this is a serious issue for cancer patients. It's pervasive, it can prevent patients from receiving high quality care. There are studies that have been done by Yousuf Zafar, by Scott Ramsey, and many others that have shown that because of financial toxicity, the quality of patients' cancer care suffers. Patients forego necessary care such as their oral chemotherapy medications or recommended physician visits and testing because of financial burden. There have been studies that have shown that patients declare bankruptcy at a much higher rate than patients in the rest of the population because of their cancer diagnosis and treatment. And although out-of-pocket costs are an important measure of financial toxicity, it's not the only measure of the financial burden that cancer patients face.

So I'm going to tell you about a series of studies that we've done to investigate financial burden among patients with colorectal cancer. These are studies that were funded by a grant from the American Cancer Society. That grant was to Dr. Morris, who's one of my mentors, and these are studies that are based on a population-based survey that we conducted of patients with resected Stage 3 colorectal cancer. And the surveys were mailed out 4 to 12 months after patients were diagnosed, and patients were recruited through the SEER registries in Detroit and Georgia.

So I'm going to tell you about four different studies that we did. The first was to develop a composite measure of personal financial burden just so that we could get our heads around how to measure our financial burden beyond just out-of-pocket costs. Then we used that measure of financial burden to look at the personal financial burden associated with complications after surgery for colorectal cancer. We further moved into looking at the employment impacts among working patients with colorectal cancer, so I'll tell you about a study that we did looking at the associations between paid sick leave and personal financial burden in these patients. And then finally, I'll tell you about a broader study that we did of job support benefits beyond just paid sick leave and their association with job retention among working colorectal cancer patients.

So I'll show you the study flow diagram for these studies. We identified just over 2,000 patients with Stage 3 colorectal cancer from the Detroit and Georgia SEER registries. These patients were diagnosed between 2011 and 2013, so a contemporary population. We sent surveys to

all eligible black patients, and then a 50% sample of eligible white patients to achieve a representative study sample. 4 to 12 months after their diagnosis with colorectal cancer, patients were mailed an introductory letter, the survey questionnaire, a return envelope, and a \$20 incentive. And we used a multi-modal Dillman approach for follow-up.

We received just over 1,300 surveys for a 68% survey response rate, which is a pretty good response rate, especially among patients with colorectal cancer. And 546 of those patients were working for pay at the time of their colorectal cancer diagnosis, so in the initial studies when we were describing personal financial burden among this population, we used the entire population of patients, and then in the later studies when we were looking at the employment impact, we used just those patients who were working for pay at the time of diagnosis.

I'll show you the characteristics of our patient sample. So you can see about half of patients were under the age of 65. This is important because although colorectal cancer is more commonly diagnosed in older patients, there have been recent studies that have shown an alarming increase in incidence of colorectal cancer among younger patients. And I'll also show you that it's the younger patients who are particularly vulnerable to personal financial burdens, so we had a good representation of younger patients in our study sample. We also had just about half of the sample were women, about a quarter of the sample were black, about 40% of the sample had an annual household income under \$50,000, and again about 40% of the sample had a high school education or less. So broad demographic representation in the study sample.

I'm first going to tell you how we created our composite measure of personal financial burden. So we started by asking patients seven binary questions about financial burden that were adapted from the National Consumer Bankruptcy Project, and you can see the items down below. We asked patients, because of their colorectal cancer treatment did they have to use savings, did they have to borrow money or take out a loan, could they-- did they have trouble making payments on credit cards or other bills, did they cut down on spending for food or clothing, did they cut down on spending for health care for other family members, did they cut down in recreational activities, and did they cut down on expenses in general.

And then we performed a factor analysis to try to determine if these seven items grouped into one factor, one measure of personal financial burden, or two or more measures of financial burden, and the first thing that we found in our factor analysis was that the item, I cut down on spending for health care for other family members, this item here, was endorsed by very few

patients. Fewer than 5% of patients checked yes to that question, and when we looked at the loading values, it didn't sort of hang together with the other items. And so when we removed that item from our questions, we found that we had good internal consistency with the remaining six questions. So we narrowed it down to six of the seven questions for our composite measure.

We also found that these items grouped into measures of discretionary and non-discretionary spending. So the items that grouped into discretionary spending were the items, I cut down on spending for food or clothing, I cut down on recreational activities, and I cut down on expenses in general. And you might argue that spending for food and clothing is not necessarily discretionary, it's not something you can do without, and I think that's a valid argument, but from the statistical standpoint of our analysis, that item did group together with the discretionary items, and so that's how we classified it. The remaining items, I had to use savings, I had to borrow money or take out a loan, and I could not make payments on credit cards or other bills, grouped together as items of non-discretionary spending. And so that's the way we constructed our measure of personal financial burden.

We then perform internal validation to make sure that our measure was accurately assessing patients' worry about their finances, and also the impact on their finances of their diagnosis. So we asked patients two questions, we asked them, how much do you worry about financial problems that have resulted from your colorectal cancer? And as you would expect, you can see from the graph on the left, that patients who had low levels of worry about their finances were more likely to report 0 or 1 measures of personal financial burden, and conversely, patients who had high degree of worry about their finances were more likely to report three or four even more items of personal financial burden. And so we found that there was a 70% correlation between our measure of personal financial burden and patients who worry about their finances, and you can see the Pearson correlation coefficient up at the top there, that was significant.

So then on the right, we asked the question, it was a yes or no question, my illness has had no impact on my finances, and again, as you would expect, the patients who said that the illness has not had any impact on their finances, the vast majority of those patients did not endorse any of the measures of personal financial burden, and on the flip side, the patients who did report an impact on their finances were far more likely to endorse more measures of personal financial burden. So this signified to us that we had a good measure, we had hit on a good



measure of personal financial burden that was valid in this patient population.

So then we used that measure to ask the question, which patients are most vulnerable to personal financial burden as they go through a colorectal cancer diagnosis and treatment? And we performed multivariate logistic regression, and what we found were the patients who used chemotherapy were significantly more likely to experience personal financial burden, the patients who experienced complications after surgery for their colorectal cancer were more likely to experience higher burden, black patients were more likely to experience higher burden, younger patients, particularly patients younger than age 50, and patients who reported an annual household income between \$20,000 and \$49,000 a year, and I'll note that that number is significant because that level corresponds to 100% to 200% of the national poverty threshold in the US.

So what you can see from the table on the right, here, is a breakout of the patients who used chemotherapy versus those who did not, and their levels of personal financial burden. So you can see the dark red bars are the patients who didn't use chemotherapy, the pink bars are the patients who did use chemotherapy. So among those patients who did not endorse any of the items of personal financial burden, about 60% of those patients were those who did not receive chemotherapy, versus only 30% who did receive chemotherapy. And then as you look-- as the personal financial burden scores increase-- increases, meaning patients endorsed more items of financial burden, you can see that the patients who received chemotherapy were significantly more likely to endorse more items of personal financial burden than those who did not receive chemotherapy.

So given that we found that it was really the younger working-age patients who were most vulnerable to personal financial burden during their colorectal cancer diagnosis and treatment, we wanted to further investigate the employment impacts among working patients with colorectal cancer. Because one of the unmeasured costs of colorectal cancer care or cancer care in general may be job loss. And we know that not only do patients who lose their jobs experience lost wages and lost incomes, which impact the patients and their families, but society also faces the loss of productivity, the loss of workers from the workforce, and there can be costs beyond just those experienced by the patient and their family.

There have been prior studies that have described long-term job loss among breast cancer patients and the economic impact of job loss among these patients, and we wanted to describe the employment impacts among colorectal cancer patients, both in terms of job

retention, job loss, and financial burden.

So the first thing we looked at was paid sick leave because we hypothesized that patients who had access to paid sick leave may be more likely to retain their jobs as they go through a cancer diagnosis and treatment, and that they may also have reduced personal financial burden. Now the reason we started with paid sick leave is that paid sick leave is arguably the most policy-relevant job support benefit. So paid sick leave is not a part of FMLA, it's not nationally-mandated, and in fact, currently 40% of US workers have no access to paid sick leave.

However, we thought that it might really make a big impact in the lives of patients as they go through a cancer diagnosis and treatment. And so we found, in univariate analyzes, that among patients with paid sick leave, here, 59% of patients retained their jobs among those patients who had paid sick leave. And without paid sick leave only 33% of patients retained their jobs and that difference was statistically significant.

So then we looked at personal financial burden as the outcome, and we conducted multi-variate logistic regression adjusting for sociodemographic and socioeconomic factors to look at the difference in personal financial burden between patients with and without paid sick leave. And what we found was that patients who had paid sick leave available had lower levels of personal financial burden, when we used that composite personal financial burden score, than patients who did not have paid sick leave, and that difference was statistically significant. And you might say, well, OK, but you just told me that patients with paid sick leave are more likely to retain their jobs, and so doesn't that retaining your job just mean you're going to have less personal financial burden? How is that associated with paid sick leave?

And so to further investigate that, we then estimated a model where we adjusted for all of those same sociodemographic and socioeconomic variables, but we added job retention into the model as well, to look at how job retention might attenuate the association between paid sick leave and personal financial burden. And as you can see, what we found when we added paid sick-- when we added job retention into the model, was that there was no difference in effects, there was no difference in the association between paid sick leave and personal financial burden, which suggests that just retaining your job is not the only mechanism for reduced financial burden for patients with paid sick leave.

And this makes sense to me just on a conceptual level and also in experiences that I've had

with my patients, because I know that when patients are able to take time away from work to attend their visits with me, to get their CAT scans, to get their chemotherapy and recover from their therapy, and not lose wages from those days away from work, to still get a paycheck, that their overall personal financial burden is reduced. So it's not just about having a job at the end of all of this, being able to go back to your job, which clearly is important, but it's also about being able to maintain your income as you go through treatment

And I'll tell you about a young patient I was treating, a patient in his 30s with two kids, who I was treating for Stage 3 colon cancer, who worked as an EMT, he worked on the ambulance. And his employers were very understanding about letting him take time off of work to get chemotherapy and to recover, and they assured him that he would have a job at the end of all of this. But he didn't have paid sick leave and he didn't have any income coming in when he was going through his treatment, and because his job was so rigorous and because he was often out on the ambulance for 14 or 16 hours a day, he really couldn't work he was going through chemotherapy, it was just out of the question.

And one day about halfway through treatment he came to me and said, listen, my wife and I can't even pay our mortgage, we can't pay our utilities, and I don't know if I can keep going through treatment because I need to bring in money, I need a paycheck. And that's really what we're talking about here when we talk about paid sick leave. Not only does it help patients keep their job at the end of it, but it helps them keep an income while they go through treatment.

So we were really excited about this finding, but we recognized that there were probably other factors that were associated with job retention and personal financial burden as patients go through a cancer diagnosis and treatment. We knew that there were probably other sociodemographic, other socioeconomic factors, and other job-related factors. What kind of job does a person have? What other jobs support benefits do they have that play into these important outcomes of job retention and personal financial burden?

So we expanded our studies and we did a second investigation, and we wanted to describe the impact of an individual socioeconomic position, of the environmental context, and job characteristics, on job retention among working colorectal cancer patients. What we really were asking was, is it who you are, where you live, or what you do that is most strongly associated with job retention during and after colorectal cancer treatment?

We also wanted to know, beyond paid sick leave, what was the relative impact of other job support benefits on job retention? So we'd showed that basically it was important, but maybe other things are important too. So we also looked at employer-based health insurance, a flexible work schedule, the availability of paid sick leave, extended sick leave, unpaid time off, and disability benefits as they related to job retention in these patients.

So I'll show you the job-related characteristics of the patient sample, and again, remember, these are the patients who were working at the time of their colorectal cancer diagnosis, because we're looking at employment-related outcomes. So this was 546 working patients, we classified their jobs as white collar or blue collar to try to get a better sense of what kind of occupation were patients doing, and really to try to get a proxy of what was the physical strenuous of a patient's job? We didn't specifically ask that, but we classify these in such a way that the blue collar jobs are much more physically strenuous jobs.

And we found that just over a third of our patient sample had blue collar jobs. About a third of our sample, 30%, did not have employer-based insurance. 43% of the sample did not have a flexible work schedule, 49% did not have paid sick leave, so even a little higher than the population base level of 40% of workers who don't have paid sick leave. 48% did not have extended sick leave, 46% did not have unpaid time off, and 43% did not have access to disability benefits.

So what we found was that the overall rate of job retention in our sample was 55%, and when we did unadjusted bivariate analyzes of job retention, we saw that there were significant patient-level sociodemographic, environmental, and job-related factors that were significantly associated with job retention. So men were more likely to retain their jobs than women, black patients were more likely to retain their jobs than white patients, married patients were more likely to retain their jobs than unmarried patients, patients who had higher income and higher levels of education were more likely to retain their jobs, and patients who had fewer comorbid diseases were more likely to retain their jobs.

When we looked at the environmental factors, we saw that there was no significant difference in job retention between our two sites, so between Detroit and Georgia, no significant difference in job retention. But we did use our SEER data to construct a composite measure of aggregate socioeconomic status to try to get a better sense of the environmental context in which these patients were living. And we found that patients who lived in the upper tertile of aggregate socioeconomic status were more likely to retain their jobs than those in the lower

tertiles.

And then when we looked at the job-related characteristics, we found that patients who had each of those individual jobs support benefits were significantly more likely to retain their jobs than patients without those benefits. Again, these are unadjusted analyzes of job retention. So we found that there were a lot of different factors that played into job retention, but again, what we really wanted to know was what were the most important, is it who you are, where you live, or what you do?

So to try to tease that out, we estimated multi-variate logistic regression models predicting adjusted job retention. So in the first model on the left, we included all of the sociodemographic and environmental characteristics that I mentioned in the previous slide, I'm only showing you those that are statistically significant here in the table. And the first thing I want to point out is that neither gender nor race were significantly associated with job retention when we adjusted for other covariates in this model, which is kind of surprising, it was not what we expected. What we found was that only education and income were significantly associated with job retention, so those with higher levels of educational attainment, and those with higher annual household incomes were significantly more likely to retain their jobs.

Then we wanted to add in the job-related characteristics to see what their effect was, and so we created a second model which included all of the same sociodemographic and environmental characteristics of the first model, but also added in the job characteristics. So we added in the job type, broken down by white collar versus blue collar, and we added in all of the individual job support benefits. And what you'll see is that education and income are no longer significantly associated with job retention, and that there were three job support benefits, employer-based health insurance, a flexible work schedule, and paid sick leave that were significantly associated with job retention.

So what this showed us was that it really isn't who you are or where you live that are associated with job retention, but it's really the job support benefits that you have that predict whether or not you're likely to retain your job as you go through colorectal cancer diagnosis and treatment. Another way of looking at this is a figure showing the adjusted probability of job retention by individual job support benefit, and you can see that the three asterisks indicate the three levels, the three measures of job support that were significantly associated with job retention in our multivariate models.

So we found that about 65% of patients who had employer-based health insurance retained their jobs versus only 30% of patients without employer-based health insurance, 75% of patients with a flexible work schedule retained their jobs versus just under 30% of patients without, and 70% of patients with paid sick leave retained their jobs versus just under 40% of patients without. You can also see that patients who had extended sick leave, who had unpaid time off, and who had disability benefits were more likely to retain their jobs than those without those benefits, but those were not significant-- those were not statistically significant in the adjusted models.

First study was subject to several limitations that are inherent to survey research. The first was that we weren't able to differentiate between elective and non-elective job loss, we didn't ask that particular question in our study. But I would argue that regardless of the reason for job loss, losing your job is a loss of income to you and your family, and can contribute to personal financial burden, and so in some ways elective versus non-elective may not be the driving factor, the most important factor here, it's really the loss of income. Additionally, we relied on patient report of their outcomes, and so our study was subject to recall bias.

We assessed job retention 4 to 12 months after the patients cancer diagnosis, the mean time that patients were completing the survey was about 8 months after their diagnosis. So it's possible that some of the patients in our study who lost their jobs may have later gone on to go back to work, but there have been a number of studies in the literature by Victoria Blinder, Reshma Jagsi, and others who have shown that early jump loss among cancer patients, particularly among low-income cancer patients, is predictive of long-term job loss. And so we think it's very likely that many, if not most of the patients in our study who lost their jobs went on to long-term unemployment. And finally, our study was geographically limited to Detroit in Georgia, but we were able to achieve broad demographic representation.

So the conclusions that we've drawn from that series of studies is that a colorectal cancer diagnosis and treatment results in substantial and pervasive financial toxicity for patients, where we refer to financial toxicity as being both the personal financial burden that patients experience, the subjective experience of financial burden, and also a major impact on employment outcomes for patients. We found that the young, working poor are particularly vulnerable to these financial impacts, and that, based on our findings, employer-based health insurance, paid sick leave, and a flexible work schedule help to mitigate the risk of financial toxicity as patients undergo treatment for colorectal cancer.

So I'm going to leave this portion of the talk with three questions and implications, and I'm not necessarily going to answer them today because I think what our work has brought up are directions for future work in this area. So the first [INAUDIBLE] is what are the real societal costs of colorectal cancer beyond out-of-pocket costs, beyond the dollar numbers that you see in the news, what does society really pay for colorectal cancer care? And what's the most effective way to distribute the financial burden of cancer and its treatment both among patients and their families, but also among the health care system in general? And finally, and perhaps most importantly, how can clinicians and researchers help to alleviate financial burden among cancer patients? Because that's really going to be the key to removing financial toxicity as a barrier to quality care and our patients.

All right, so I'm going to kind of take us back to where we started, and I'd like to spend the next maybe 5 to 10 minutes, so that we have time for questions at the end, telling you about where I'm going next.

So I told you about where I've been, I started out looking at quality of care from the systems perspective, and cost from the systems perspective, and then I moved on to looking at quality of care from the patient perspective, and cost and financial toxicity from the patient perspective.

But my clinical experience has taught me that the patient is not just the person who is sitting in front of you in the exam room, and that our patients experience cancer and cancer care in a much broader context, in a context of a social network of family and friends and neighborhood and community that impact the quality of care that patients receive. And I know that those supporting people can be instrumental in shaping the care that our cancer patients receive. And furthermore, I realized that it wasn't just patients undergoing active treatment for colorectal cancer, but that survivors of colorectal cancer, patients who have made it through treatment also have unmet needs and are facing disparities in quality of care that need to be addressed. So I became more interested in looking at the quality of care after a colorectal cancer diagnosis, and looking at the people around the patient who might impact that quality of care.

I'm particularly interested in factors that influence the quality of surveillance care for survivors of colorectal cancer. So why is surveillance so important for colorectal cancer? One of the really cool things about colorectal cancer, and one of the reasons I love taking care of cancer patients, is because we have the chance to potentially cure patients with metastatic disease.

This is unique among solid tumors and it's really exciting. So for patients who have limited recurrences in their liver or their lungs, we still have a chance of treating those patients for cure, but we, know that finding those recurrences early, before they become symptomatic, impacts the survival of patients, and so surveillance is really important. These patients need to be surveyed for recurrences that are asymptomatic.

And what do I mean by surveillance care? I mean the physician visits that patients get every three to six months for five years after they finish treatment. I mean getting blood tests for CEA that they get four every three to six months. I mean the CAT scans of chest, abdomen, and pelvis the patients get to look for asymptomatic recurrences, and colonoscopy that patients get it first annually and then maybe every three to five years afterwards. And it's that whole package that makes up surveillance care, you can't just get your doctor visit and your CEA, you need everything to really find those early recurrences that we can still treat for cure.

The problem is that a substantial proportion of patients do not get the surveillance care, so this is data from a study that I collaborated on with colleagues at the University of Pennsylvania and we used SEER-Medicare data to look at receipt of surveillance among patients with Stage 1, 2, and 3 disease.

So I guess those colors are not projecting very well but the top line is green and those are patients with Stage 3 disease, and I'm going to focus on those, because those are the patients for whom we know, when we have clear evidence, that intensive surveillance leads to improved survival rates because we find those early recurrences. And you can see from the graphs on the left that when we look at non-imaging surveillance, so that's looking at doctor visits, CEA levels, and colonoscopy, taking CAT scan out of the picture for a minute, only 50% of patients are getting recommended surveillance care with all of those modalities. This data-- this study, we followed patients through 2007, but I can tell you that if you trend the data forward the numbers don't get any better.

If you look at the graph on the right, we added in CT imaging so that this is looking at adequate surveillance including doctor's visit, CEA, colonoscopy, and CAT scans, and the reason that there's a dip here, that 2005 is important, is because 2005 is the year when the major societies, ASCO and NCCN included surveillance as part of their recommendations-- including imaging as part of their guideline-recommended surveillance care. And so you can see that when imaging went into the guidelines, we dropped down to a quarter of patients, 25% of patients, who are receiving adequate surveillance care. Those numbers, if you follow



them forward, have gotten a little bit better, but they don't go over 50%. So there's 50% of patients who aren't getting adequate surveillance, and perhaps are having loss of life because of that, because we're not finding disease early enough when we can potentially still cure it.

So we know that there are many factors that can impact the quality of surveillance care, I come back one last time to the Mandelblatt model. So studies have shown that on the patient level, their sociodemographic and socioeconomic status plays into variations in receipt of surveillance care. Black patients are less likely to receive surveillance care, patients of low socioeconomic status, patients without insurance, and patients with poor geographic access to medical care.

The problem is that we as clinicians can do very little to intervene upon those factors, we can't change those factors for patients. So I started to think about what else can we leverage to increase receipt of lifesaving care in these patients? And I think it really lies in the individual context of the patient, the partners of patients, which perhaps is an untapped resource that we as clinicians can leverage to help patients get high quality receipt of surveillance care.

And I drafted a conceptual model for this, is the conceptual model that laid the framework for my KO7 proposal, and I argue here that it's really partner engagement, which is the center box, that is where we can go next in trying to find a resource to help patients get surveillance care. There have been a number of studies, one just a couple of months ago, published in Cancer that showed that married patients have much better survival than unmarried patients with cancer.

Some of that might be endogeneity, right, healthy people and people who care about their health marry other healthy people and other people who care about their health. But I don't think that explains all of it, and I hypothesized that there's a level of engagement of the partner in health care that may lead to high quality outcomes. So I think partner engagement consists of three key factors. I think it's the partner being informed about the patient's recurrent risk and the benefits of surveillance. I think it's the patient being involved in the surveillance sorry the partner being involved in the surveillance care process, and I think it's the partner being aware of the patient's values and preferences that all lead into receipt of high quality surveillance care.

And I think there are certainly patient-level factors and partner-level factors that play into partner engagement and play into receipt of high quality care, but it's that partner engagement

that I'm focusing on. So I'll show you the specific aims for my K07 project which is going to be starting very soon and I'm very excited to get working on. So my first aim is to identify, through in-depth interviews, factors that influence receipt of surveillance from the perspective of survivors and their partners. So I'll be interviewing survivors and their partners to talk about facilitators of and barriers to surveillance care.

And then using what I learn in those interviews, I'm going to develop a survey, a dyadic survey, that we distribute to survivors and their partners, to determine the partner-specific factors associated with a high level of partner engagement in the patient surveillance care process. And we hypothesize that there will be some vulnerable patients who are at risk for having their partners have low levels of engagement in the patient care process. I think minority patients may have partners with lower levels of engagement. I think male partners may be less engaged in the process than female partners. We'll find that out.

And then our third aim is to determine, through a survey of colorectal cancer survivors and their partners, the relationship between level of partner engagement and patients receipt of surveillance. And we hypothesize that patients whose partners have a low level of engagement in the surveillance care process are less likely to get high quality surveillance care. The reason I think this is important to tease out is because I think it provides opportunities for intervention.

And my long-term goal with this is to develop a dyadic intervention targeted at patients and their partners to try to improve partner engagement in the surveillance care process and increase the receipt of surveillance care among patients. And so that's why I'm really excited to get going on this work and get to a point where we can use these untapped resources to improve the quality of care for colorectal cancer survivors. And that's what I'm going to leave you with today. So I'd like to thank you and just once again acknowledge all the folks who have helped make this happen and I'll take any questions.

**SPEAKER 2:** [INAUDIBLE]

That's interesting, so no, NSAIDs has not traditionally been considered a part of surveillance care, but it's an interesting point because I think you're alluding to the fact that there have been studies that have suggested in some cities shown that the use of NSAIDs may reduce recurrence risk in patients who've undergone treatment for stage 3 colon cancer. I'm not sure that NSAID use necessarily plays into receipt of surveillance care or is sort of a standard

recommendation at this point but it may become one so it would be very interesting.

**SPEAKER 3:** [INAUDIBLE] Christine?

**SPEAKER 1:** Yes.

**SPEAKER 3:** Wonderful work, thank you for coming back.

**SPEAKER 1:** Thank you.

**SPEAKER 3:** I want to see if I understood this correctly. When I looked at one of your tables, you were looking at three or four characteristics that were predictable outcomes, [INAUDIBLE]. Health insurance, extended [INAUDIBLE], flexible schedule, [INAUDIBLE].

**SPEAKER 1:** This one? Yeah.

**SPEAKER 3:** I would think that number 1, 2, and 3, sort of go together. Does your data allow you to separate these out?

**SPEAKER 1:** Yeah.

**SPEAKER 3:** I assume that the person who has a flexible work schedule and paid leave of absence also has health insurance.

**SPEAKER 1:** Right, so yeah, that's a really good point. We actually looked at that, we looked at correlation, trying to tease out where their correlation between specific job support benefits that tended to hang together. And actually, interestingly, there was a fairly good spread, so there really weren't any particular benefits that sort of clumped together, and what that gets at, I think, is sort of the good versus bad jobs. You would anticipate that patients who have quote good jobs, who have health insurance, and paid sick leave are more likely to retain their jobs and have less financial burden, just as a basis of having that good job, and that the opposite would be true for patients with bad jobs.

But that actually didn't play out in the data. So we saw that when we looked at the occupation type, white collar versus blue collar, that was not significantly associated with job retention, and that these job support benefits didn't hang together in any particular patient group, and also that the sociodemographic and socioeconomic status no longer become statistically significant when we look at those job support benefits. So thinking about those as a proxy for bad jobs, you would think that it would be the low SES patients who have those bad jobs and

are less likely to retain their jobs in general, but that didn't play out in the data. So I really think that it is these job support benefits that are leading to the effect of job retention.

One further bit of analysis that we're working on right now is doing a propensity score analysis to try to further tease that out, to tease out the endogeneity between these variables, and looking at the propensity to have these job support benefits as they relate to job retention, so that's the next step in this.

**SPEAKER 4:** [INAUDIBLE]. What does this mean for people who get their insurance through the Affordable Care Act? [INAUDIBLE]

**SPEAKER 1:** Right. So the question was what's the implication for patients who get their insurance through the Affordable Care Act, which may have some different characteristics than sort of standard or traditional employer-based health insurance and doesn't have these other benefits rolled into it. And I think that's exactly right, so employer-based health insurance, I think probably looks very different from a lot of the Affordable Care Act policies, and so that would be sort of an interesting next step of study, maybe in a few years once things have kind of settled out with the ACA and the marketplace insurances, but the other policy impact of this work is that the fact that with the Affordable Care Act more patients are going to have insurance, period.

Now, whether it's the same as employer-based health insurance or not is debatable, but that, I think, to my mind makes paid sick leave and flexible work schedule even more important as policy initiatives, because those aren't rolled in with health insurance, we're not going to be able to mandate national health insurance, as much as some people would like to do that but we might be able to make paid sick leave or a flexible work schedule nationally mandated, or we might be able to roll those in with another implementation of FMLA or something like that. And so I think that just serves to further highlight the importance of those particular benefits in the financial burden and job retention of working patients with serious illness.

**SPEAKER 5:** [INAUDIBLE]

Well, I can tell you that what we know from the data, so we didn't specifically ask the question of why they lost their jobs. We know that about a quarter of the working patients who were working at the time of diagnosis reported that they were disabled at the time that they completed their survey. So in my mind that probably relates more to surgery and chemotherapy effect, and really sort of their physical ability, perhaps, to do their job.

And so that might play into the more physically strenuous jobs, which is what we are trying to get out with that white collar, blue collar classifications. So that might be part of that. Your job is physically strenuous and you're just not physically able to do it anymore. I do think that time away from your job is another important factor and I think and I don't have the data to back this up but I think if you think about sort of the employment world and the employment literature, where probably impacts folks the most are in low-wage, low-opportunity jobs. Think about the person who works part time at Wal-Mart or something, who if you said to that employer, I need to take six months off, might just say, well, there's not a job for you anymore.

So I think that's part of it too. And then there certainly could be things where I think patients probably re-prioritize after a cancer diagnosis, and decide that they don't want to spend their time working anymore, whether they're able to make that decision or not. But I think that might play into it.

And we know that 7%, so a very small number, but 7% of our patients did retire between the time when they were diagnosed and the time they took the survey. So that might be, you could consider patients who were near the retirement age anyway, get a cancer diagnosis and just decide to retire but that's a very small number of patients. So I think there are a lot of different reasons and that's just some of them. We don't have all the data to tease that out.

**SPEAKER 6:** Just out of curiosity, I'm wondering the lack of difference that you're seeing between a blue collar and white collar [INAUDIBLE] two locations where you were, with both Detroit and the Atlanta area [INAUDIBLE] union jobs. I'm wondering if that played in to your retention and health insurance [INAUDIBLE].

**SPEAKER 1:** That's really interesting because we don't have any way of controlling for whether patients are in a union, but I think that clearly would be a big factor that might play into that between-- in the blue collar jobs. So that's a really interesting factor but unfortunately we just don't have that data.