### HELP CHART WITH ANSWERS AND TRANSCRIPT

#### Question 1
The adherence data in CML showed that:

<table>
<thead>
<tr>
<th>Choices</th>
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<tbody>
<tr>
<td>A. Patients who were &lt;90% adherent had the ability to have a complete molecular remission.</td>
<td>8</td>
</tr>
<tr>
<td>B. Missing 1-3 doses/month did not affect response</td>
<td></td>
</tr>
<tr>
<td>C. There was a difference in responses in patients who were &lt;90% adherent to their drug. ✓</td>
<td></td>
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<tr>
<td>D. A and B</td>
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#### Question 2
Adherence is affected by:

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<th>Choices</th>
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<tbody>
<tr>
<td>A. Complexity of the treatment regimen</td>
<td>10</td>
</tr>
<tr>
<td>B. Need to be fasting</td>
<td></td>
</tr>
<tr>
<td>C. Ability to take drug with alcohol</td>
<td></td>
</tr>
<tr>
<td>D. All of the above ✓</td>
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#### Question 3
Factors that may decrease adherence include all of the following EXCEPT:

<table>
<thead>
<tr>
<th>Choices</th>
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<tbody>
<tr>
<td>A. Strong family social support ✓</td>
<td>11</td>
</tr>
<tr>
<td>B. Lack of healthcare insurance</td>
<td></td>
</tr>
<tr>
<td>C. Low literacy level</td>
<td></td>
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<td>D. A chronic disease diagnosis</td>
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#### Question 4
All of the following were mentioned as explanations for nonadherence in young adults EXCEPT:

<table>
<thead>
<tr>
<th>Choices</th>
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<tbody>
<tr>
<td>A. Feeling embarrassed in front of their peers ✓</td>
<td>20</td>
</tr>
<tr>
<td>B. Feeling invincible</td>
<td></td>
</tr>
<tr>
<td>C. Preferring a natural approach</td>
<td></td>
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<tr>
<td>D. Being afraid of rebuke from their physician</td>
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#### Question 5
The multiple myeloma study on financial toxicity published in *Lancet Hematology* showed that:

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<tbody>
<tr>
<td>A. 71% of patients had at least minor financial burden ✓</td>
<td>17</td>
</tr>
<tr>
<td>B. 51% of patients borrowed money for medication</td>
<td></td>
</tr>
<tr>
<td>C. 10% of patients utilized savings to pay for treatment</td>
<td></td>
</tr>
<tr>
<td>D. All of the above</td>
<td></td>
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</table>

#### Question 6
Up to ___ of patients who take 5 or more medications are nonadherent:

<table>
<thead>
<tr>
<th>Choices</th>
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</thead>
<tbody>
<tr>
<td>A. 25%</td>
<td>20</td>
</tr>
<tr>
<td>B. 36%</td>
<td></td>
</tr>
<tr>
<td>C. 59% ✓</td>
<td></td>
</tr>
<tr>
<td>D. 74%</td>
<td></td>
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#### Question 7
Studies have shown that African Americans consistently report poorer cancer knowledge that European Americans and are less likely to believe in the efficacy of treatments:

<table>
<thead>
<tr>
<th>Choices</th>
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<tbody>
<tr>
<td>A. True ✓</td>
<td>21</td>
</tr>
<tr>
<td>B. False</td>
<td></td>
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#### Question 8
Depressed patients:

<table>
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<th>Choices</th>
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</thead>
<tbody>
<tr>
<td>A. Are more likely to be adherent with medications ✓</td>
<td>22</td>
</tr>
<tr>
<td>B. May have substance abuse issues ✓</td>
<td></td>
</tr>
<tr>
<td>C. Are more likely to have health-promoting behaviors</td>
<td></td>
</tr>
<tr>
<td>D. Follow through with surveillance screening</td>
<td></td>
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#### Question 9
Motivational interviewing may contribute to improved adherence by utilizing:

<table>
<thead>
<tr>
<th>Choices</th>
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</thead>
<tbody>
<tr>
<td>A. Closed-ended questions</td>
<td>Q&amp;A</td>
</tr>
<tr>
<td>B. Reflective listening</td>
<td></td>
</tr>
<tr>
<td>C. Patient engagement</td>
<td></td>
</tr>
<tr>
<td>D. B and C ✓</td>
<td></td>
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#### Question 10
The Leukemia & Lymphoma Society offers:

<table>
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<th>Choices</th>
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<tbody>
<tr>
<td>A. Information specialists and personalized clinical trial searches</td>
<td>25, 26 &amp; 27</td>
</tr>
<tr>
<td>B. Online social networks for patients and healthcare professionals</td>
<td></td>
</tr>
<tr>
<td>C. Professional education programs</td>
<td></td>
</tr>
<tr>
<td>D. Myeloma and oral medication adherence resources for patients</td>
<td></td>
</tr>
<tr>
<td>E. All of the above ✓</td>
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Slide 1 - Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

Lauren Berger:
Good afternoon everyone, I'm Lauren Berger, senior director of professional education and engagement at The Leukemia & Lymphoma Society national office.

Slide 2 - Welcome and Introductions

The Leukemia & Lymphoma Society is committed to improving patients’ quality of life through advocacy, research, and education and supporting patients. We advocate to fund and to accelerate the discovery and development of blood cancer therapies and to ensure that patients have coverage through insurance for their care. To date, The Leukemia & Lymphoma Society has invested more than $1 billion in research to advance therapies and save lives. I think that for each one of us, what it's all about, is to save lives and to help people improve their own quality of life.

We are very pleased to provide individual resources and support for patients, both through our national office and our chapters around the county. Many of our programs are online. Several of our programs are in person, such as this, and then many support programs and opportunities are for patients throughout the country. All of the resources we provide for patients, professionals, caregivers, families, are free. That's part of our responsibility, which everyone should be able to access the services that we offer.

We know that you are supporting patients each day in your treatment centers, in your hospitals, in outpatient clinics, and we know that the patients really rely on you for support. We know that they hear from you about information. They ask you questions. They come to you for both psychosocial support, as well as medical support, with questions about their disease, about their treatment, and you are key, along with the rest of the healthcare team to providing the best quality of life for the patients. So, we’re happy to be able to partner with you in that endeavor and to be a resource for you as you work with patients and families on a daily basis. We know that your role is so important and you are there for them, along with their caregivers.

This afternoon we are going to talk about adherence to oral therapy for cancer, the role of the healthcare professional. And as you all know, many new cancer therapies are now taken orally. An estimated 25% of anticancer therapies in clinical trials have been designed to take orally. This number is expected to climb to 50% and more. Oral therapy plays a critical role in helping to improve the quality of life for patients, making it
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

Cara Kondaki, LCSW, CBPN-IC, OSW-C
Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD
May 3, 2016

Lauren Berger:

easier and convenient. There are less office visits. But also there is a shift in responsibility from the healthcare provider to the patient. The patient is responsible to not only understand what their therapy is but to work with their healthcare team who can hopefully help them to remember to take their meds, to get their meds, to be able to access them, and so there are a lot of different issues that come up, and I think more and more we’re hearing that as patients are on oral chemotherapy and other therapies. We are here to help them. We have to be sure they understand it, they adhere to it, and they agree to it in order to be able to go forward. It often involves a family member or a caregiver to help them. And it also involves the whole team: the nurse, the social worker, the physician, the pharmacist, and many others.

We also know that the role of the oncology pharmacist, especially with oral chemotherapy and other treatments, will evolve, and it will grow. And so it’s important for the team to communicate, to work together along with the patient.

Slide 3 - Faculty
I am now pleased to present our speakers and to introduce them.

Slide 4 - Disclosures
Cara Kondaki is from Cleveland Clinic, and I am going to have each person mention a little bit about themselves. Lisa Nodzon, is from Moffitt Cancer Center, and Jennifer Powers is from Walgreens Company. I’m going to turn the program over to Lisa now.

Slide 5 - Oral Adherence for Optimal CML Management
Lisa Nodzon, PhD, ARNP, AOCNP®:

Hi everybody. I’m Lisa Nodzon, a nurse practitioner here in Tampa, Florida at Moffitt Cancer Center. I work in the Department of Malignant Hematology. The disease we focus on is chronic myeloid leukemia as well as chronic lymphocytic leukemia. I will talk a little bit about the role that I play with patients in terms of oral adherence, and then Jennifer will talk from the pharmaceutical perspective and then Cara, from the perspective of a social worker.

I think you’re going see throughout today’s presentation that it really does take a village when it comes to these patients, especially with the increasing numbers of oral oncolytics that are on the market, and then, at least from the medical side of things,
Lisa Nodzon, PhD, ARNP, AOCNP®:
we're no longer just putting the IV in the patient's arm to know that the patient's getting therapy. We’re actually trusting them from home to take the drug, and you'll see with some patients, if the drug makes them feel worse, they're not going to want to take the drug, and you probably see that with the patients that you interact with.

Slide 6 - Decline in Deaths Related to Ph+ CML Since the Utilization of TKIs
We'll talk about adherence to oral therapy for cancer and particularly with patients with chronic myeloid leukemia. and it can behave rather indolently. Patients are on oral chronic therapy for life. And you'll see looking at this bar graph here, that while the number of CML cases has remained relatively the same since 2001, it's a rare disease; around 5,000 cases per year. It can be pediatric and can also be in the adult population.

Slide 7 - Poor Overall Survival for CML Patients that Progress to Blast Crisis Despite TKI Therapy
What has changed is actually the number of deaths due to CML per year. We once used oral chemotherapy and a different agent for CML, known as interferon, but ever since the advent of the oral TKIs, the tyrosine kinase inhibitors, with Gleevec® (imatinib) being the very first one, we’ve really changed how we manage patients with CML. It is unheard of that a patient nowadays would require any sort of chemotherapy for their CML, only if the disease were to progress on. But, being that the disease is controllable with an oral drug, the key point is that we want to keep our patients going on that oral drug. The majority of patients when they get diagnosed are in the chronic phase. However, for patients that progress on to accelerated phase or blast crisis phase, otherwise known as an acute leukemia phase, prognosis is relatively very poor, roughly along the order of nine months even in the face of the oral drugs.

So, when we meet patients in the clinic and they are newly diagnosed or they're not doing well in their current therapy, we always talk to them. The first question we have for them is, “Are you taking your drug?” Because you don’t want to accuse the patient, but at the same time, you have to find a reason if they’re not responding the way they should be. Especially with CML being that the mainstay is oral TKI therapy, the drugs make them feel relatively bad. And most patients at diagnosis don’t feel bad. They are instantly found to have a high white count when they present to their primary care physician or maybe the spleen is slightly enlarged. They don't feel bad. And now we’re going to treat them with a drug, and we’re telling them, “You’re going to take this the rest of your life.” And the drug can make them feel bad. And over time when patients
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Lisa Nodzon, PhD, ARNP, AOCNP®:
get very complacent about their therapy, especially with CML, they stop taking their
drug because they think things are fine.

That’s where that key point comes in, where it takes a village, the chronic education to
the patient, and everyone plays a part in that, whether it be the pharmacist, the patient’s
not getting their drug refills on time. What’s going on? We control refills in our clinic by
only giving three per visit because that is how we monitor our patients, every three
months, or maybe they can’t afford their drug. And so we always reach out to the social
worker to say, “Hey, can we help?” Or reach out to a funding or foundation support like
The Leukemia & Lymphoma Society. Can we get co-pay assistance? Because TKIs
themselves, per month, can be over $10,000. And Jennifer will talk a little bit more
about that.

Slide 8 - Long-term Adherence to Imatinib is Critical for Achieving Molecular
Response
For a disease that’s treatable, the key point is you want to keep the patient going on
drug. When they looked at different studies, with CML being a very heavily weighted
disease, looking at oral adherence patterns in patients, they found that we can equate
the patient’s response with those that are adherent. And when they looked at particular
studies using pill caps that have little electronic devices in the cap, you can monitor how
often is that patient actually taking the cap off their drug and correlate that with
compliance. What they found was that for patients that were less than 90% adherent to
their drug, there was a difference in terms of response. So, if you think about what is
90%, you’re thinking in a 30-day period, that’s just one to three doses. And if we think
about our diabetics and our patients with hypertension, even patients that take
antibiotics, we know they’re missing doses.

But for a disease like CML, missing one to three doses a month is critical because the
data has shown that it can affect their response. If you look at the graph on the right,
the difference is even more striking, because with a disease like CML, we’re moving into
an era where there are a lot of discontinuation trials, meaning can we get patients to a
point potentially curing them and take them off drug? Perhaps give them a drug holiday
because of the effects of these drugs that have long term on the body. They found that
for patients who were less than 90% adherent, their ability to ever have this complete
molecular remission, meaning a complete remission, was nearly 0%. And that’s just
patients that were missing less than 90% of their dosing.
Lisa Nodzon, PhD, ARNP, AOCNP®:
Slide 9 - Adherence Rates and Dosing Frequency
Patients over time get very complacent with their CML therapy because things are looking good, but they're not seeing the overall picture, and that is can we take them off drugs one day, which is kind of where some of the CML therapies are trying to move towards. We know that for patients that take different dosing patterns per day, their adherence rates can fluctuate. If we look across a lot of disease spans, HIV, breast cancer, hypertensives, patients that have multiple doses per day, their adherence patterns, and their adherence rates go down.

In CML, some of the drugs are given once a day, some are given twice a day. And for patients who have issues with compliance, we ask ourselves, can we switch them out to one of the TKIs that are given once a day and get them off one that’s given twice per day, in an attempt to improve adherence patterns? We tend to find in our practice, it's the male in the middle-age category that seems to be less compliant with dosing. When we prescribe one of these drugs, it’s something that we take into consideration. We don’t want to stereotype the patient, but in our clinical experience, we know that it's usually harder for the younger patients to try and do twice-a-day dosing. So, we think about that. It’s important if you’re trying to choose a drug for a patient, never be afraid to interject, when the provider is saying, “We’re going to consider this medication,” never be afraid to say, “You know what, I’m a little worried about their compliance” or “can you do a once-a-day dosing” because, again, the data is showing that we can affect patterns.

Slide 10 - Specific Factors Affecting Patient Adherence with Oral Oncology Therapies
We know there are a lot of different factors in oncology patients that affect why they’re not adherent to a drug. Right there at the top you see disease. Is it a chronic disease? Is the patient, perhaps, going to die from something else, because that may be why those patients tend to be less adherent. So, in a disease like CML where you start them on therapy, the tendency is they’re going to die of something else, not their CML. Those patients over time will become less adherent, versus a patient with acute myeloid leukemia, those patients are going to be really adherent, because about 50% of those patients die per year. So, we take that into consideration with the chronic diseases. Severity of symptoms, I mentioned earlier. Most CML patients at diagnosis are asymptomatic. But now we’re going to give them a drug that has the potential to cause them some pretty serious side effects, so the patients are going to kind of skirt themselves by and be less adherent.
Lisa Nodzon, PhD, ARNP, AOCNP®:
As I mentioned, the asymptomatic disease, treatment, the complexity of the regimen. Is the drug taken with food? Is it taken fasting? Can you take it once a day? Can you take it twice a day? Maybe if you take that drug, you can't take something else with it, so the patient’s got to change around their whole schematic of their medications, and that could be difficult for patients. The number of daily doses. of immediate benefit. Some patients, when they present at diagnosis, they're asymptomatic. So, you're giving them a drug that’s supposed to make them feel better? For those patients that are not readily getting the benefit impact on lifestyle, that’s an important one too. If it’s twice-a-day dosing, maybe they can’t take it with alcohol. So, for patients that want to have wine or beer in the evening, well now you’re telling them sorry, you can’t do that anymore. That becomes a big factor as well.

Socioeconomic, low health literacy, something that I know we all encounter. We meet patients from all different sorts of educational backgrounds, and we have to make sure that we're speaking their language, that we’re not talking over the patient. When we’re discussing drugs with patients, discussing regimens, making sure we’re trying to avoid some of the medical jargon that we take for granted because we use it every single day. And sometimes you really have to bring it down for the patient and make sure that they understand. And often we have them repeat it back to us. Okay, you understood how to take the drug. So, what was that again that we said?

You want to make sure that you have this two-way conversation with the patient, so when they leave the room, we’re all on the same page. And sometimes you’ll find out that patients, they come back, and they say something, and you can see how they interpreted what you said. So, we always try to make sure we have this two-way in the room with the patient, especially when we’re talking about new drugs. And again, meeting all different members of the health team, they’re going to hear the same thing but a couple different ways. So, the thought being the message will take home at some point.

Lack of family social support. We like for our patients, when they arrive, preferably to have a caregiver with them, because the caregiver is going to hear 80% of the conversation, the patient is going to hear 20%, especially at new diagnosis or patients in the relapsed setting. It’s just going to go way over their head. But the caregiver is going to get the key take-home points, and then on the car ride home, they can discuss it over and over again. And sometimes we even get where the patients arrive alone and
Lisa Nodzon, PhD, ARNP, AOCNP®:
the caregiver calls us afterwards. “Oh, my mom was in today, can you please discuss the therapy with me because I’m the one that takes care of my mom” or “I’m the one that puts out her pills”, so if you can always have a caregiver there, or if you want to delay the conversation until the caregiver gets there. We try to be as amenable as possible for our patients. You want to make sure that the message really gets out.
The access to the pharmacy or facilities. Is it a drug they can go up the street and pick up or is it a mail-order drug or does it only require a specialty pharmacy? Sometimes that can have an impact too on patients being adherent. We have a lot of problems in our clinic for TKIs for patients that are on Medicaid. For these particular drugs, they are only allowed to have a 30-day supply. One of the drugs only comes in a 28-day pouch packet, which, when I met the reps the other day, I asked them why is that when there are 30 days in a calendar period? The little things like that can cause patients to go without drug.

Well, sometimes missing again, those one to two doses has a big impact on the patient. So, making sure that those refills are coming in a timely manner. And I always say to the patient, “Any hiccups with your refills?” Because that’s where you want to intervene, and you’ll hear these horror stories when insurance companies do this or they want another prior authorization. It’s almost crazy, and I thought to myself the other day, if I actually add up, take a typical CML patient and how many doses get missed per year because of delays in refills with insurance prior authorizations, it’s probably a huge savings on the insurance company’s behalf, because those patients are not getting the drug every 30 days. And Medicaid seems to be the most difficult for us here in the state of Florida for our patients.

Sometimes they only want to give the patients a two-week supply. And I’m like, “But they have CML, we’re doing 30 days”, and it’s a constant fight with the insurance company. We recently had a girl relapse into accelerated phase because Medicaid did not give her drug on time because the lady sitting behind the desk said, “We’re only going to give 15 days because we couldn’t get a hold of the patient”, but the patient was calling and we were calling. So, it made no sense. Well, now the poor girl is 23 years old in accelerated phase CML with two twins that are three years old, so horrible stories. Horrible stories.

Lack of health care insurance, that’s a big one as well too. We know for our patients that don’t have commercial insurance, we have to reach out to foundations. We have to reach out to the pharmaceutical companies and try to get assistance for patients, and
Lisa Nodzon, PhD, ARNP, AOCNP®:
they seem to be all over the map. Does someone take the house into account? Do they take the car? Things like that become really, really important. We have several patients that have undergone divorce just to make their income patterns change so they can get assistance. So, horrible stories.

Again, you really have to dive deep with your patients when you first prescribe things to them. And we know it can be a sense of pride for some of them, maybe the $50 co-pay is too high. Maybe it’s not. Maybe it’s $500. So, when we prescribe the first script, we send it in-house just because I can reach out to the pharmacists and say, “Hey, did Mr. Smith pick up his medication today?” And if the answer is no, then my next thought is because the co-pay is probably too high, and we know with our elderly patients that can be an issue. You know, sense of pride or a sense of dignity, and we don’t make anyone feel uncomfortable, but we want to let them know right off the bat when we prescribe these drugs, they’re very expensive. We don’t know what your insurance company is going to do.

There are the patient factors as well. Some patients will say, “I don’t want chemotherapy.” You have to educate them. This is not a chemotherapy agent. This is an inhibitor. So, again, just trying to dive back into the patient’s background and ask what is their belief? Some patients don’t want to take toxic things. They’re very into herbal remedies. And our answer for that is always we’d all be billionaires because we’d all come up with an herbal remedy and cure cancer. The point is we can’t. So, I do describe to the patients these are the drugs that are going to maintain your disease control and prolong your life. There are a lot of patients that get very involved into these herbal remedies and don’t want to take toxic things. So, again, you really have to kind of pull that out of them as well when you meet patients, because you’ll see they come from all different backgrounds. The fear of side effects. As a practitioner, that’s my job to manage the side effects of the patients, so we watch them very closely. The more side effects, the less adherent you expect the patient is going to be.

If you hear from a patient, you’re reaching out to him, you’re checking up on Mr. Smith, and we get phone calls all the time from the pharmacist or from the social worker or from a nurse on another floor saying, “You know, I was talking to Mr. Smith, and he’s having a horrible skin rash, but he hasn’t called the clinic.” That’s someone that you’re going to want to reach out to, but if you hear it from the patient, you want to report that back to the team to let them know maybe you want to see Mr. Smith sooner because
Lisa Nodzon, PhD, ARNP, AOCNP®:
he’s got a rash. So, in the back your mind, you know that patient’s not going to be taking the drug. Again it really takes a village to pull from all different people because patients feel, well, if I tell one person that one person must be telling everybody. Again just keeping that communication wide open is very important.

Then there’s the healthcare system itself. The pharmacist has to speak to the physician, the physician has to be speaking to the patient, to the social worker, and to the infusion center, and then to the one doing the refills and the prior authorizations and the nurse practitioner. We all have to learn to communicate, and at the end of the day, most problems come down to what? Poor communication. Again, it’s very important for the patient. Lack of positive reinforcement. For our patients when they can see they’re meeting certain milestones, we celebrate that with them. Things must be going really good, you must be doing a good job taking your medication, not having any problems with refills. Must be doing A-OK with your side effects. You must have a good pattern down. Maybe you’re taking it at night or you’re taking it twice a day.

Slide 11 - Predictors of Poor Adherence
So, we give them positive reinforcement like that and then we give them their results as well, because the patient can actually see I am responding to this drug. Eventually, every now and then, you’ll hear patients say, well, I missed one or two doses a month. Well, that’s okay. Then you want to pull out the data saying, well, this is what happens when you miss one or two doses a month. So it’s really specific and individualized to the patient when you talk to them and you’re finding out that they’re taking an oral drug and maybe why they’re not taking it, but patients will tell everybody a different story. Predictors of poor adherence. As I mentioned, in our males age 40, we know that they’re going to be the least compliant when it comes to the CML drugs. So, again we think about that.

The poor provider-patient relationship. If the patient feels they can’t tell you things, then you’re never going to know, and that’s where the patient may tell the social worker, may tell the pharmacist. Again, the village approach. The presence of barriers to care or medications. We know that’s a no-brainer. Patients that don’t have the financial resources or can’t make it out for the clinic visits. We will try to prolong things and try to prolong their drug as well. I mentioned with a disease like CML, because the refills go along with how we monitor them every three months, we don’t give more than three refills out because we want to see the patient back and it’s just kind of our little mechanism to make sure the patient comes back. Missed appointments. For any
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Lisa Nodzon, PhD, ARNP, AOCNP®:
patient that misses a clinic visit with us, we do reach out to them and say, “Hey, you missed your appointment today. Perhaps you didn’t get the notification”, rather than assuming the patient just didn’t want to show up, and then we’ll reschedule them at that time or find out if there was some other issue.

Complexity of treatment. We’ve talked about the cost, which is a big one. And Jennifer will talk more about that. The lack of belief in the treatment itself. Again, we need to do a thorough, thorough education with our patients when we start them out on any sorts of therapy. What are we doing and what are our goals? Especially in oncology, we always have to have that discussion with the patient. What is our goal? You know we can treat, treat, treat, treat, treat, but what is our goal? At the end of the day is it quality of life? Is it disease control? Are we going for the cure or are we just going for palliative therapy? Side effects of medication. This really has to be discussed. As soon as we prescribe the drug to our patient, we know it’s also reinforced by the pharmacist when the patient picks up the drug or if it comes from a specialty center. The specialty pharmacists also do a really good job of calling the patient in a couple days and checking up on side effects. So, that’s a huge one, especially when it comes to CML, because of the side effects the TKIs.

Inadequate follow-up. This is always a concern. Sometimes in the community setting when patients get referred to us for disease progression, we find out there was a lack of attention to follow-up. The patients weren’t being monitored appropriately and had somebody have just looked at some labs or just looked at certain tests, they would have seen that the patient was progressing. The question was why were you progressing, and you’ll hear the patients say, “I couldn’t afford my medication.” Those are very heartbreaking stories that I’m sure we all have in the room. Treatment of asymptomatic disease. We talked about that with CML. These patients could be relatively asymptomatic at diagnosis, as is true for some of the other hematologic malignancies. Presence of cognitive impairment. Again, what are the patients thinking? What is their belief pattern in terms of what kind of drug are we giving them? “Are you giving me something toxic and I am going to take this forever? This drug is going to give me cancer.” You name it, we’ve heard it across the board as I’m sure you all have for why patients don’t want to take their drug.

The psychological problems. Sometimes these could be difficult too, that’s where you want the caregiver to really be involved with the patient to make sure if the patient has some dementia or if the patient is just forgetful that you have a caregiver
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Lisa Nodzon, PhD, ARNP, AOCNP®
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May 3, 2016

Lisa Nodzon, PhD, ARNP, AOCNP®:
there. So, that concludes my part of the presentation. And next I’m going to turn it over to Jennifer.

Slide 12 - Financial Toxicity and Adherence Barriers
Jennifer Powers, PharmD:
I’m Jennifer Powers. I work with Walgreens Specialty Pharmacy. I have been a pharmacist in one of our local specialty sites where we collaborated closely with the healthcare team, the nurse staff, as well as financial coordinators, nurse navigators, and social workers specifically for co-pay assistance, not only getting patient medication, but then how can we keep patients on medication and break down some of the barriers that we often find in adherence whether it’s related to side effect management or co-pay. For my part of the presentation I will be going over financial toxicity and some of the barriers that it presents in adherence.

Slide 13 - Navigation Through Insurance is Complex
We all know insurance navigation is very challenging, whether the patient is commercially insured or if they have Medicare or Medicaid. It’s a challenge navigating through this process. Oftentimes we see in the commercially insured patient and in Medicare/Medicaid prior authorization. Nine times out of 10, the oral medication is going to require a prior authorization and oftentimes we even see the prior authorization needed multiple times within the calendar year. It’s not uncommon at times for this to be a lengthy process. With all of the new oral agents in the market today, there are over 50 oral agents today, 25% to 30% are going to be in oral therapy within the next decade.

Oftentimes we see a little bit of a lag time with insurance companies in updating their clinical question sets to obtain a prior authorization. Sometimes you can have a little bit of a hiccup in that process in obtaining a prior authorization, or an appeal is required. I’m sure you probably have all experienced the appeal process and had to navigate through that. Sometimes it requires multiple levels of appeal. It really depends on the patient’s plan, whether it’s commercial or state funded or Medicare, the navigation process can be quite complex. And unfortunately, what we see in that process, are a lot of patients will come to us and they have already looked at the cost of the medication and they give up even before going through this process. “Oh, I can’t afford that. “You know, I may as well die.” Unfortunately, oftentimes I’ve heard that, and it’s really sad that at the onset of starting oral therapy, oftentimes they’re already in a financial distress and concerned about how they’re going to pay for medication.
Jennifer Powers, PharmD:
Slide 14 - Defining Financial Toxicity
I want to look at the term financial toxicity and what that actually might mean in this space. Financial toxicity can be defined objectively as the direct cost associated with treatment for the cancer patient as well as the subjective cost, and those would be the costs associated with any concerns that might be a result of getting to their care. So whether it’s transportation, whether it’s support of meds, but it’s not the direct cost to treat the cancer. As a matter of fact, the Family Reach Foundation annual report last year noted that 59% of their grant funding went to assist patients with housing. So, 59% of the grants they awarded was actually used by patients to pay for mortgage and rent because of that subjective cost that’s associated with cancer treatment and many of the advocacy programs have wonderful resources for patients that can be utilized to assist with some of the subjective costs. LLS has a wonderful program, the Susan Ling Pay It Forward Travel Assistance program that will assist patients and some of those transportation costs of going back and forth to care. Definitely, both areas can impact the patient outcomes and can create barriers to adherence in patients having access to medication.

Slide 15 - Financial Toxicity has Multiple Impacts to Patient Outcomes
We know that financial toxicity has multiple impacts to patient outcomes. If we look at the quality of life that the cancer patient has who is undergoing financial toxicity. They may forego certain expenses that they once may have really enjoyed. Vacations, they may no longer take vacations which certainly can impact their overall health. And Carol will talk a little bit later about psychosocial barriers to adherence, but patients who are not able to work as frequently as they once were, that certainly is impacting their quality of life when they’re not able to do something that they may have once enjoyed. We know that with financial toxicity, there is treatment compliance that becomes a concern. I know I had a prostate cancer patient who was taking oral therapy and he takes four a day, and he was a Medicare patient, and he was coming up on the new year, so we all know that the new year new deductible start over, new out-of-pocket expenses come over and that shift goes over to the cancer patient. And unfortunately, this gentleman, he made too much money to qualify for any type of advocacy group to fund his over $2,000 co-pay in January.

So, his answer was well, I will just take one a day and I’ll stretch that 120 pills over the course of four months. We stopped him, to not have him do that, and we looked at his out-of-pocket expenses that were related to his medical costs. We looked at the subjective costs associated with his care. Although he did not qualify for any advocacy
Jennifer Powers, PharmD:
program to pay for his co-pay, what we were able to do is work with the manufacturer to help support a sample. And for that patient, that elongated that co-pay for him. He was able to get a free month's supply at no charge, which stretched his out-of-pocket expense, and he was happy with that. The important thing for him was he was not willing to tap into any of his savings.

Slide 16 - A Correlation Between Bankruptcy in the Cancer Patient and Mortality
One thing that we find with some of the older population, in the men, while they are providing for their families here, they certainly want to provide for their families when they're gone, and so, if they are saving and they worked very, very hard to build up a savings for their family when they're gone, to dip into that to pay for their treatment, oftentimes they do not feel it's worth it. So, definitely financial toxicity can have an impact on treatment compliance. And recently there have been studies to link financial toxicity with survival, and we will look one of those studies here. There is a correlation between bankruptcy and the cancer patient. Data suggests that cancer patients are two and a half times more likely to become bankrupt than the noncancer patient. And the adjusted hazard ratio for mortality in cancer patients who do become bankrupt is 1.79%. And this data was obtained, either these associations persisted even after excluding patients with distant stage disease at diagnosis.

This is really kind of startling if you think about bankruptcy being really the extreme end of financial toxicity. The data doesn't really look at all of the in-between, all of the patients who maybe throughout the course, they are barely getting by, but maybe they haven't filed for bankruptcy. How many times have they adjusted their dose to prolong their treatment? Even with the data that we have here on bankrupt patients, it is still a little skewed, because it doesn't address those patients who are not at that very extreme end, but all of those steps that lead to bankruptcy. I had a patient who was being treated for lung cancer, but he was on the anticoagulant to prevent clotting. And he was getting it at a retail pharmacy and paying over $600 a month. And when he came to us it had been several months into his treatment. He came to us and I had learned that day that he had sold everything he had, and the last thing that he sold was his wedding ring. But he was not bankrupt. But yet he had already sold everything he had, his most precious valuables he had sold just to pay for his treatment. So, again patients don't always report bankruptcy but they are definitely going through financial distress and it can certainly impact their treatment.
Jennifer Powers, PharmD:
Slide 17 - Financial Toxicity in Insured Patients with Multiple Myeloma
This study here is very interesting. It was in the Lancet Haematology last year. It looks at financial toxicity in insured patients with multiple myeloma. And I think it’s really interesting because multiple myeloma patients today are living longer on treatment. Last year we saw a boom in multiple myeloma in patients on dual therapy. So, we’re not looking at just one co-pay, but now we’re looking at two co-pays. And if you look at some of the combination therapy, for example, Revlimid® and Ninlaro®, both of those are oral agents, oral specialty medications that multiple myeloma patients are taking today, taking longer to treat their cancer. So, this study here took a look at 100 multiple myeloma patients, and it showed that 71% had at least minor financial burden. So, 71%, at least some form of financial burden they encountered. Twenty-one percent borrowed money to pay for medication. Forty-six percent utilized savings to pay for treatment. And so I’ll just reference this here, if you think back to my prostate cancer patient, 46% utilized savings to pay for treatment, but in my prostate cancer patient, remember that wasn’t worth it to him. He was willing to forego treatment rather than dip into his savings. And for 46% of patients to be impacted by the cost of medication to cause them to dip into their savings, that’s a substantial number.

Thirty-six percent applied for financial assistance, and 59% had higher than expected costs for treatment. So, 59% of patients were not expecting the costs that they incurred through their cancer treatment. Again, I find that to be a very high number whenever you think of the impact that financial toxicity and the financial burden can cause on the cancer patient. With that, it definitely lends to the fact that the time is now to talk about financial toxicity with the patients. I’m sure you guys are speaking to your patients regularly about this, but at what point in care is this addressed? And it varies. It’s not consistent. Not all practices have a social worker, not all have a nurse navigator to navigate for the patient in this process. And with oral medications coming to market today with an average non-insured cost of $10,000 or more for a month’s supply, the time is now to talk about financial toxicity. But it’s difficult, and I know as a pharmacist it’s difficult.

Slide 18 - Discussing Financial Toxicity with Cancer Patients
I think for healthcare professionals in general, it’s not a comfortable topic to talk about finances. I know we didn’t have a class on it in pharmacy school. It’s not something that is a very natural topic, but if you look at it and equate it to a health-related side effect, which it is if you consider the fact that it decreases quality of life, it can increase mortality rates, and it certainly has negative patient outcomes when it impacts
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May 3, 2016

Jennifer Powers, PharmD:
adherence. And if you look at it as more of a health-related issue, then it’s a little bit easier to have those conversations with the patient. It’s also a little bit easier for the patient to have those conversations with the healthcare professional as well. It is a natural side effect of the cancer treatment. You start to see it a little bit differently. It’s a little bit easier to engage in those conversations.

Unknown Speaker:
We had one patient who was in the donut hole with Medicare and that posed a huge problem during that…

Jennifer Powers, PharmD:
Right.

Unknown Speaker:
Gap.

Jennifer Powers, PharmD:
Right. And did the patient qualify for any assistance?

Unknown Speaker:
No.

Jennifer Powers, PharmD:
No? What are some of the things you tried during the... Did you work with the, obviously the advocacy groups, I’m sure.

Unknown Speaker:
Well, with this particular patient, they did have the money.

Jennifer Powers, PharmD:
Okay.

Unknown Speaker:
So, it wasn’t like, you know, they were in a situation that they couldn’t financially afford it. They didn’t want to.
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May 3, 2016

Jennifer Powers, PharmD:
Right, right. They didn’t want to dip into their savings. And we’ve had, we’ve had situations like that as well, and what we’ve been able to do, because you know this, the advocacy groups all have a threshold of out-of-pocket and what they can make and what’s the maximum amount they can make. And the same with some of the assistance programs that help with the subjective costs. And so, what we’ve been able to do is to look at patients’ finances and see where we can assist in other areas, so then it frees up money to then pay for their medication.

Unknown Speaker: That’s a good idea.

Jennifer Powers, PharmD:
And so, it’s a way that, it’s obviously not addressing the objective cost, the cost of the medication, the direct cost, but by assisting with some of the other associated costs for our patients, it’s made them feel that okay, well I can balance this because then they’re not seeing it, just come from all directions. And I don’t know if that is helpful. I don’t know if anyone else has encountered that and how anyone has overcome that challenge. I know the donut hole is a tricky one, which is why it’s really nice when the patient qualifies for advocacy, because oftentimes that first month it will put them in the donut hole, get them out of the donut hole, and all the while the patient is not having to pay that co-pay. So, it’s really nice when that works out, but when it doesn’t, it certainly is a challenge and patients may just decide it’s not worth it.

Unknown Speaker:
When we’re in situations like that, we reach out to the pharmaceutical representative, and we let them know, “Hey, we have this patient, this is the story,” because some pharmaceutical firms are very generous when they consider finances. They may not take the car or their house into account.

Jennifer Powers, PharmD:
Right, right.

Unknown Speaker:
Because the house could be fantastic, but what they’re bringing home is not, because like she’s saying, you have to look at different things, but as a last resort we, not as a last resort, but you reach out to the pharmacy representative and say, “Hey, this is the case that we have,” and see where they can get involved, because oftentimes they can
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Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD
May 3, 2016

Unknown Speaker:
assist there too, because for some patients to get them through maybe you can get them free drug.

Jennifer Powers, PharmD:
Right.

Unknown Speaker:
Just to get, just to push them through when they run into these donut holes like that, because that’s a big issue to be a thing of the year, so never be afraid to reach out to that pharm rep because they want your business too.

Jennifer Powers, PharmD:
Absolutely. Absolutely. And everyone’s different too and each pharmaceutical company is different in their patient assistance program that they have. So, that’s a great point.

Unknown Speaker:
And I think sometimes with patients, because some of the assistance programs are generous with their income, maybe they’re having problems with other things in their life like paying the electric bill or something like that, and I’ll say try to go for the co-pay assist, at least it gives you extra money in your pocket, so that you have that and you can use it for other things. So that’s always a good thing to keep in mind as well.

Jennifer Powers, PharmD:
I think a very important thing to remember too is that we empower our patients to be aware that the resources are out there, and to not just simply accept it’s not covered, and then they walk away. I know with our pharmacy and the specialty pharmacy, what we’re able to do is really navigate and find those resources for the patient, and if I can reference my lung cancer patient who is taking the anticoagulant, again, he was going to a non-specialty pharmacy getting his medication. He did not know the resources were available. So, he’s paying $600 a month for his co-pay and didn’t think to question why. What can I do? What options are there?

So, I think it’s important today that we make sure our patients just ask questions. If it’s not covered or with Gleevec coming generic. I don’t know if any of you have had any situations with that. Just in February with the first generic of the oral-targeted therapy, but for a patient to go to the pharmacy and then suddenly say, oh, well it’s not covered, it could be something as simple as their computer system automatically switched it to
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Cara Kondaki, LCSW, CBPN-IC, OSW-C
Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD

May 3, 2016

Jennifer Powers, PharmD:
the generic, but the insurance hasn’t caught up to the fact that there is a generic, and they’re still paying for the brand. We would not want the patient to just say, okay, walk away, and then, as Lisa mentioned earlier, miss a couple doses because it only takes one to three doses to have a significant impact.

So again, just empowering our patients to know the resources are available, know to ask questions, and not to be fearful of asking questions, and having an active part especially as the responsibility of care is shifting more to the patient.

Unknown Speaker:
When you were talking, I was thinking about the process that we have at our facility and I felt that I wanted to share it. Every patient who starts an oral chemotherapy regimen with us automatically gets a referral to our financial coordinator, and what he does is he will talk with the patient, he will let them know their options as far as assistance with the drug companies or with the foundations. He will get those resources for them. And we are in a pretty rural area, so it’s very rare that our patients don’t qualify for that assistance. Last year, he was able to get about $1.8 million dollars in free medications for our patients at our center, and that was him working part-time. He just switched to full-time. We are in Lebanon, Pennsylvania, which is kind of near Hershey, like Hershey Park. But it’s worked very well for us to put that process in place and our patients have been very thankful.

Jennifer Powers, PharmD:
I think that’s great, and I really like what you said there at the very beginning. You’re encountering the patient, engaging the patient early on with this topic. So again, empowering them with the resources so that they know what’s available to them, and, you know, they can have kind of an expectation of what their treatment will cost and then what resources are out there to help them navigate through that. I think that speaks to the fact that bankruptcy is the very extreme of that spectrum, but everything in the middle, we want to make sure we are addressing it before it goes into the crisis stage. I think that’s a great practice to have.

Unknown Speaker:
We rely really heavily on patient stories and patients talking about these issues, and that’s a really tough thing to ask a patient to do, to talk about the challenges that they face, the financial issues that are happening, you know, while also trying to go through treatment. We rely a lot on social workers who are seeing these patients on a daily
Unknown Speaker:
basis to talk generally about these issues, but having patients come forward and talk about their experiences. It’s tough. It’s a very sensitive subject.

Jennifer Powers, PharmD:
And I think it’s interesting, you remind me of a patient that I recently encountered who is insured and he has a manageable co-pay, but he still has an ongoing fear of what if he loses his job. What if his insurance isn’t the same next year as it is this year, and what if he then has to start paying out-of-pocket when he’s been on this treatment now for 10 years and he is doing very well. It’s hard, you would never know that initially meeting him, but after you speak to him for a little while and he gets comfortable, he starts to engage and share some of this information. So, I think it’s something that it’s easy for us to think, “Oh well, $25 is not too much or $100, that’s so much better than thousands of dollars,” but really not allowing the patient to set what they are comfortable with and sharing their concerns and their fears, because it certainly all impact their distress and their journey, so that’s a great point.

Jennifer Powers, PharmD:
Alright, well with that, Cara is going to come up and speak to you now.

Slide 19 - Psychosocial Factors Affecting Adherence to Oral Cancer Therapies
Cara Kondaki, LCSW:
I’m a licensed clinical social worker. I work at Cleveland Clinic in Westin. I think we could talk all day about the financial concerns we’ve had with patients. We tried to split it up a little bit and look at different things, but I started maybe 11 years ago. They never had a social worker in the oncology department when I started there. They didn’t know what to do with me. And then they found out all the things we can do, and one of the first things I remember is helping patients to get this great drug called Tarceva® that was an oral drug but was so expensive for lung cancer. And so then I got all the Tarceva patients and that was really part of what I did. We didn’t have a financial counselor at that time. So, I kind of was the financial counselor.

And we find out that the doctors thought, “Oh, this is great, we can get you some help, the social worker can help you,” and then that was what I was getting called for a lot. When Xeloda® came along, I was getting a lot of calls because it was expensive. Now we have more issues, and we were talking about that earlier, that there isn’t a lot of assistance for Xeloda and that’s a big problem for a lot of patients on these oral medications. But as social workers, we also understand that there are other
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Lisa Nodzon, PhD, ARNP, AOCNP®
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May 3, 2016

Cara Kondaki, LCSW:
psychosocial factors that can affect adherence. It’s not just financial, although it’s huge. And that’s why I think the distress screening that we’ve been doing and that’s been coming through the COC is so very important. It really helps us to see what our patients are having trouble with and it may not just be financial. And the distress screening started back in 2005, and I think it was the Canadian Cancer Control Group that said that distress screening was the sixth vital sign.

Nursing is so important and all those components, but looking at the psychosocial factors that go along with cancer patients, and not just their blood pressure and their temperature, but the other things, financial toxicity and the things that impact them. Some of the barriers that we address are not just financial, and I’m going to go a little bit over that now, and also the importance of the team. So, we would get on the phone to talk about this, and there’s just so much interplay between the nurse and working with the financial counselor or a pharmacist and the doctor, and how we can work together to get what’s best for patients. I don’t think we can underemphasize how important working together in the group setting is and how it does impact our patients in a positive way.

Slide 20 - Psychosocial Factors Affecting Adherence to Oral Cancer Therapies
Financial issues are huge, and they’re devastating. They can devastate families. I had a patient just this week that came in, downsized to a smaller apartment, has two small children. He’s a mechanic, so he can’t do heavy work. His wife can’t take anymore time off from work, and now he has to have surgery and she can’t even be with him. And they’re just having a really, really hard time. So, I did get them some help with their rent, their mortgage for one month just to kind of tide them over. Those things are just so important. But we know finances aren’t the only factors and actually, more than 125,000 people die each year just due to medication non-adherence, and that’s twice the number that are killed in car accidents. And nine out of every 10 hospital outpatients are taking prescribed medications improperly. So, that’s nine out of 10. That’s a lot.

If you think about it, I’m wondering to myself do I take my own medication improperly because that’s a lot of patients. Poor adherence has been linked to unnecessary disease progression as they were saying. It causes complications which contribute to prolonging or additional illnesses. I kind of morphed from being the only social worker into a certified breast patient navigator and there are two social workers now and a financial counselor. So, I deal a lot with breast cancer, and it breaks my
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May 3, 2016

Cara Kondaki, LCSW:
heart every week when I see patients that decide not to take their oral endocrine therapies and maybe they come back with a recurrence or maybe they come back with metastatic disease because they didn’t understand the importance of taking it.

Part of my job is to get them back into the office to see why. We know they’re not taking it when they stop coming in for their follow-up visits, because that’s when they come in for their refills. And so a part of my role is just to get them back in to talk to the doctor to make sure they can get some kind of follow-up care. We also know with elderly people not taking their medications properly can reduce their functional abilities. It causes more nursing home admissions. They have three times as many doctors’ visits as other patients. So, it does cause a lot of difficulty. Older patients who can’t afford their medications may split their pills, cut back on their doses we were saying earlier, or go without for long stretches of time.

Many seniors take five or more medications a day. They don’t know what the purpose of every medication is. They don’t understand the consequences of not taking those medications as prescribed. They may feel good and reason they don’t need to take the medication. They might say that the treatment benefit is small compared to the cost, and so they don’t want to take that. But up to 59% of those who take five or more medications are nonadherent, and our patients typically do take a lot of medications, don’t they? They take anti-nausea medication, sometimes pain medications, maybe they also have diabetes, hypertension. So, they’re not just taking cancer meds. They are taking all these meds, and so it is likely that they’re not taking some of them correctly.

And it’s not just seniors who take medications improperly. Young cancer patients delay medications, skip medications. They feel they don’t want toxins in their body. They want to be more natural. They don’t want to interrupt their youth. They’re invincible, right? It’s going to be okay. We had a very young patient recently and he dropped off the map and came back. He said, “You know, I felt so good, so good. I haven’t felt this good in a long time and I stopped taking my medication.” He actually came to me instead of the doctor because he was nervous about going back to the doctor. His mom had said, “You really need to go back and see the doctor.” So, he called me and he goes, “I’m nervous. I don’t want to go see her because she’s going to yell at me.” And I said, “Well, I’ll pave the way for you, but you do need to come see her.” So, I paved the way because she would have yelled at him. I said, “Evan’s coming in, but he hasn’t been taking his meds,” and unfortunately he did progress.
Slide 21 - Psychosocial Factors Affecting Adherence to Oral Cancer Therapies

So, these are the kind of things we see in younger patients too, which are so sad. But I don’t think it’s just that there’s a lot of literacy issues with our patients. Each practice is different. When we first started out, and still in our practice it’s mainly the doctors that do the teaching on oral medication, the oral chemotherapies. Sometimes in a lot of smaller offices it’s physicians who are doing the education and not nurses, and we do have our nurses doing the chemo education, but these oral cancer treatments, not so much. So, sometimes the patient, they don’t understand or maybe the doctor doesn’t have all that time to spend with them like the nurses do when they sit down with them and go through everything. We know that a patient’s education needs to be individualized, and it has to be tailored to them, and they have to use the teaching methods that are going to work best for them, and maybe during a quick, 30-minute office visit when they want them to take this drug, they’re not going to get that message across, are they?

And they don’t understand all the things. They give them the nice little kits and they have the little inserts, but that doesn’t mean they’re reading them. I come from South Florida. There’s a lot of Hispanic, Creole patients. They have multiple challenges on their own. Educating them, I don’t fluently speak Spanish. I know un poquito, but I don’t speak Creole, and neither do my doctors. We do have some Spanish-speaking doctors, but how much time are they spending educating these patients? The challenge is to make sure that the patients are well informed, that they’re supported, they’re capable of managing their medications, but we know that gaps occur every day, right? I have some background in renal dialysis and working with renal patients. And they have really come a long way because those patients take a lot of medications, and they really do use that team approach on a weekly basis to educate patients. They get the nurse, the doctor, the social worker, and the dietician, and now they have pharmacy involved, and they do a team approach, and it really does help the patients adhere. They have education in visual with pictures as well as written, so whatever the person feels they can best manage. And so that really helps them to adhere better, and I think maybe we’re moving towards this model, and I’m going to talk a little bit about that at the end. How some cancer centers are now looking at that model of doing education on a group basis.

And we know that the relationship between patients and their healthcare practitioners is paramount, but a lack of trust can cause adherence issues. Look at Evan, it’s not that...
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May 3, 2016

Cara Kondaki, LCSW:
he didn’t trust her, but I think he said some issues in communicating. There are never any issues with doctor-patient communication. I mean, that doesn’t happen, right? No, it happens every day. And that’s where social workers come into play, to kind of bridge that gap and help patients. Language barriers, low literacy, cultural, religious beliefs; they all play into how patients perceive the ability to take medications, and it does alter their outcomes. It can affect adherence. We do get a lot of people, especially where I am, that want to do the natural route, holistic, and they don’t want to put these types of medications in their body, and so they don’t take them.

There have been studies that show that African Americans consistently reported poorer cancer knowledge than European Americans and are less likely to believe in the efficacy of treatments. And so that’s another concern, and I talked about this with my intern, who is African American, and she said absolutely, she said you should hear in the community how people don’t want to take medications, they just are very concerned about the side effects. Many patients avoid medications or reduce the dosage. They fear adverse side effects as Lisa was saying, but some concerns are side effects that we hear about. They don’t want to be sedated or tired. “I don’t want to be out of it.” How many times do you hear that? With our older patients, constipation can be a real concern. They worry about that. Sexual problems, that comes up all the time where patients have quality of life issues, and so they may talk about it to us, maybe not the physician.

Slide 22 - Psychosocial Factors Affecting Adherence to Oral Cancer Therapies
But we can’t really underestimate the role depression plays in adherence. The estimated odds of a depressed patient being nonadherent are 1.76 times higher than that of a non-depressed patient across 31 studies. So, depressed patients were not going to comply

So, as social worker, that’s part of our role with the team to talk about, well this patient’s really depressed and, you know, this is why they’re not taking their medication. It does adverse adversely affect them: anxiety, distress, depression. They all affect it, and, in fact, noncompliance is three times greater in depressed patients compared to non-depressed patients. They can’t integrate their cancer diagnosis with their treatment. They’re not going to integrate that and they’re less motivated towards self-care. They are less likely to exercise and do all those things that cause endorphins that make us feel better. They may not quit smoking, which is going to adversely affect them. They might have more substance abuse issues. They’re not going to do those health-
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Cara Kondaki, LCSW, CBPN-IC, OSW-C
Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD
May 3, 2016

Cara Kondaki, LCSW:
promoting behaviors like getting out, moving, eating healthy. They're not going to do those things, and so that's going to adversely affect their ability to take their medications. They don't follow through with surveillance screening. I see that every day. I'm on the phone every day, “Well, could you just come in and see the doctor?” She goes, “Oh, I don't want to come in. I'm not taking that pill. I'm not going to take it.” I mean, I get that all time. “That's fine. Don't. Come in, at least come in and talk to the doctor.” So, they don't follow up with their six-month expected follow-ups, and that's where I come into play a lot. They don't use community resources. The things that could really help them by coming to a group or maybe getting involved or talking to a mentor on the phone, all the things we advocate for. How many times do you hear that, “No, I don't want that. I'm not going to do that,” because they're depressed. All those things that could really assist them.

They have difficulty making plans. They don't make decisions, and they have a poorer tolerance for the side effects. So, if people in general have bad acceptance of side effects, a depressed person is more so going to have that. Other barriers associated with poor adherence are, again, medication beliefs. We did talk about that a little bit. Substance abuse issues. You know you see that with someone that's an alcoholic, that they're just in general not complying. But, I am finding more recently, and I don't know about you and you can chime in, is even accessing psychiatric specialists with all the changes in the healthcare law and the managed healthcare, and now they have to go through these clearing houses to get maybe a counselor in the community, but they may not have access to a psychiatrist right away or someone that could really help them to manage these depressive symptoms.

So, I'm finding that it's just harder and harder to access quality psychiatric care for my patients. Anybody?

Unknown Speaker:
Yes.

Cara Kondaki, LCSW:
It's not just me down in south Florida then, okay. Because, you know, they have these issues and they say, “Look I called all four people you gave me, none of whom take my insurance.” And then I say, “Well, alright, let's call your insurance.” And when you call them, and I'm not downplaying us at all, but a lot of times they want to send to an LCSW when I want them to go see a psychiatrist. And they'll say, “No, you have to start here.”
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

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May 3, 2016

Cara Kondaki, LCSW:
And so I’m like, “Well, great, but I’m here, so let’s move to the next step.” So, I think that that’s a big barrier.

Also, again, the elderly. They may have visual or cognitive deficits, memory deficits, physical limitations. I don’t know if I brought it over with me, but a study just came out last week showing that, in fact, depressed patients are more likely to have dementia. Isn’t an interesting? And I thought wow, that’s pretty interesting, so, like the chicken or the egg, which came first? But they’re saying that depression can lead to dementia, so there’s more cognitive issues that we have to deal with on a daily basis. Also, studies show that people who live alone comply less with medication regime. We know that because we’re always looking for support systems, right? We’re always looking who can help you. Who do you have to talk to about this? Who is going to help you at home? How many times do we order home health for people to go out and do medication evaluations on patients so that we can make sure that they’re taking their medications. I like to order it for chemo-related side effects. I’m not sure if we can do that for an oral chemo, but I know for chemo patients I do it all the time just to get a nurse out to check on them at home.

So, again, patient education. Monitoring, involving family members or caretakers can dramatically improve adherence in patients undergoing treatment. And again that team approach to reinforcing adherence at every point in the continuum is really imperative to identifying these barriers and addressing them in a timely manner. Right? So, that’s why we get called in. Again, back to distress screening. That’s why we like to do it at different points in the continuum. The head of our cancer committee, she’s always saying, “Kara, I think there’s overlap with the distress screening.” She said, “How many of these patients are getting it two or three times?” I said, “What difference does it make if they get it two or three times?” And she goes, “Because we’re reporting numbers.” I go, “It doesn’t matter.” I said, “Let me tell you how many times I’ve had a low distress in the surgeon’s office because they get screened when they’re doing the breast surgery visit because they’re in shock, so they’re low. And by the time they get to radiation or chemo, it’s like 9, 10, 9, 10, off the charts. So, it doesn’t matter if we’re capturing it. We’re helping them, right?”

We’re always looking for that support system to see or see what is causing those problems for that patient to try to help them and move them on to the next level so they can take their medications. What are some of the strategies that we can do? I will say that when I was looking at all the research, a lot of it came from the Oncology Nursing
Cara Kondaki, LCSW:
Society, which is great. They’re taking the lead on this, but as social workers we need to look at some of this too. Wouldn’t it be cool to look at that interplay between the depression distress screening and see how it affects the adherence with the oral medications? This is an area where we could really take the challenge and see how we play into that.

But the ONS did talk about a study. It was a large community-based private cancer center in Massachusetts, and they did an oral compliance program, which included not only oral chemos, but hormonal agents, and it was a combination of in-person education, take-home packets of educational materials, and follow-up calls. And they gave them a lot of written materials, but they also followed up with them. They told them when to call the doctor’s office. They went over the side effects. They gave them personalized calendars to help them remember to take their meds, and then they had a nursing teaching visit similar to what they did for IV chemo. And before this program the nursing staff really didn’t have much involvement with the patients taking oral drugs. But after that, they did show that the communication had improved and patients felt more comfortable calling in and talking about the side effects. And part of this was teaching the nurses to do motivational interviewing. So we know that motivational interviewing uses more patient engagement. It may better contribute to improved adherence, and we know there are several therapeutic skills that we use during motivational interviewing, such as reflective listening, open-ended questions, which nurses can also use during their visit to try to help patients and to build a collaborative partnership. And what they found when they did this was that nurses tended to spend a significant amount of time trying to convince the patient to take the medication and trying to change their behavior instead of setting their own goals and seeing the value in change.

So, that’s what this was looking at. We know that you can’t really successfully modify patient’s behavior unless they buy into it and they want to change. Motivational interviewing really respects patients’ self-determination, acknowledges autonomy, and recognizes that it is the patient that is going to decide whether they’re going to change. And it can be incorporated into normal conversation and use this technique to help engage and empower patients, and establish a strong therapeutic relationship that can help them with their goals. And obviously, again, the financial screenings really important so it’s great that, we have a financial counselor now. I call her my SWIT (social worker in training), because she does a lot of referrals to community resources.
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

Cara Kondaki, LCSW, CBPN-IC, OSW-C
Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD
May 3, 2016

Cara Kondaki, LCSW:
and things and we work together. But it’s really important that they get that training, and maybe they should get that screening also for oral chemo.

So, I like what you were saying that when they get the oral medications that they go for financial. I don’t think we do that yet. They do it for all the chemo patients, but why wouldn’t you, because these drugs are so expensive. So, again the team approach and reinforcing and communicating at every step in the process can’t be emphasized enough, and I think together we can really help patients, because there are so many new oral chemotherapies coming down the pike and we’re getting new ones all the time. What can we do then as a group to help this? Do you have any other suggestions?

Unknown Speaker:
With younger patients…

Cara Kondaki, LCSW:
There you go.

Unknown Speaker:
Utilizing technology. So, different tools on their iPhones can be really helpful. I’ve had physicians ask the patients to email them when they’ve taken their medication every day. But, I mean, that’s been in kind of extreme circumstances where we know people have stopped taking their oral chemos, so it’s sort of an intervention to keep the person compliant. But, definitely technology I think.

Cara Kondaki, LCSW:
And that was part of what I read was saying, look at what the person likes as far as education. If they’re a really visual person, they may want a calendar or something like, that but if they’re techie, I mean how many of these younger kids? They might like something like a daily reminder on their phone to take it and what time. So, it’s a great point.

Unknown Speaker:
I like what you said about the motivational interviewing and trying to make sure that our colleagues, you know, are versed in those skills even if it’s an introductory type thing. Even providing like monthly, we do monthly education sessions. We like take turns writing a bulletin. So, that would be a great topic. At least for me, I’m brainstorming of
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

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Jennifer Powers, PharmD
May 3, 2016

Unknown Speaker:
something that I could do to provide some education for the rest of the staff in our building.

Cara Kondaki, LCSW:
They have a new RN class at our hospital, and so they always ask me to come because I’m the navigator. And I always ask them, “What are the signs of depression? When you see your patient, what do you do when you think your patient is depressed? Do you know what to do?” Because I think that sometimes they’re afraid, you know. “Oh, I don’t know quite what to do or who to call,” and so we try to empower them and say, yeah, you can call. You have social workers in the hospital, but if you want me to come over, I’ll come over. Let’s just get involved early so we can try to help these patients and get them on track so that they can move forward with their treatment.

Unknown Speaker:
I think in addition to motivational interviewing, cognitive behavioral therapy, particularly for those clients who are depressed, and I learned it here at AOSW probably 20 years ago, because we didn’t have as many medications to help manage side effects, but in particular I have developed sort of a specialty with women on endocrine therapies, because of course, it disrupts sleep. All the early menopausal symptoms. And it really, It is not only effective in helping them manage the side effects, but it really does give them a sense of empowerment that I think often is what people feel is taken away from them by taking medication. Somehow it’s not in their control. So, CBT is really helpful for giving people that sense that they actually are in control and can manage their symptoms better.

Cara Kondaki, LCSW:
That’s a great point, yeah, because there are quality of life issues with the endocrine therapies. That’s why a lot of people stop taking them.

Slide 23 - Strategies that May Be Effective for Long-term Adherence
Jennifer Powers, PharmD:
Well, I think a lot of this, a lot of these strategies have been touched on with the discussion in the room and the various presentations. Obviously, reinforcement is huge, and as the social worker here mentioned earlier, just the patients on endocrine therapy, data suggests that if they are less than 80% adherent, then their risk of mortality increases by 10%. The thing we have to look at is that it is long-term, and we are seeing more and more therapies and more and more cancer types being treated.
Jennifer Powers, PharmD:
chronically. And so, taking that experience and applying it to other cancers that are being treated more chronically, I think it’s important for us to reinforce the teaching that we provide to the patient at the beginning, but then also at each point of their treatment when they come in. When they come into the pharmacy, just reemphasizing to them the importance, the goal of treatment, and to understand their perception as well, as the treatment is going from IV to oral and the patient is having to self-manage their therapy, oftentimes their perception of oral treatment is very different. They don’t expect to have the toxicity that they might have with IV chemo. They don’t expect it to be significant if they miss a dose here or there, but we know that data suggests otherwise. So again, checking in more regularly with them, reinforcing the value of maintaining of the therapy and being adherent to their therapy is very important at each stage, multiple stages throughout the course, not just at the beginning, but reinforcing that. And then working very closely with the healthcare team. I know that we proactively will contact patients before their refills are due to work through any barriers that may come up whether it’s related to cost or a new prescription is needed, maybe it’s expired or the refills have run out. At that time we can also engage and speak with the patient about any side effects and communicate that back to the provider’s office, so again really closing any gaps that may exist as cancer treatment overall shifts from the IV office-monitored to the patient self-managing their treatment.

Lisa Nodzon, PhD, ARNP, AOCNP®:
The biggest key today, like when I was asked to do this is how the patient will come into contact with several different people of the team, right? From the scheduler, all the way to the pharmacist, to the financial counselor, to the nurse practitioner to the physician, everybody. And the patient will develop different relationships with everybody as well, so the patient might share a little bit with this one person or a little bit with another person. And then the key, of course, becomes the communication, to make sure that everybody across the board is on the same page, because at the end we want the best for that particular therapy and all patients are different.

You know, some patients are very easy to manage and some are very difficult to manage, and some you think are going to be easy and they are the most difficult, and so everyone’s different across the board. And I think just understanding the resources that are available to help the patient, because not every patient needs financial help. Maybe they’re good in that department, but maybe they have a lot of issues with
Lisa Nodzon, PhD, ARNP, AOCNP®:
depression and we know cancer patients in general, the day they’re diagnosed, depression and fatigue are probably the two biggest symptoms that they have. So, we understand that when we see the patient in clinic and when you’re communicating with them, we always take that into account, and referring when necessary. But again, just understanding the resources that are available...

Cara Kondaki, LCSW:
Right, right.

Lisa Nodzon, PhD, ARNP, AOCNP®:
For the patient becomes key because it can have a huge impact on disease control, and like I was saying earlier, patients that are missing doses of their therapy can have very poor outcomes, and it’s hard to think about that nowadays. A treatable disease, you can die of something else, and it’s a cancer, but just because the patient is not taking their drug. Like Jennifer had touched on, patients tend to think that because it’s not an IV drug, it’s not as toxic or, “It’s okay if I miss a dose” because patients that are on chemotherapy tend to be more compliant with showing up for that visit, and even if you want to move them out a day, they’re like, “No, I have to be on time for my chemotherapy. I can’t miss a day.” But when you put them on oral drugs, oh, okay I’m missing a few doses. They don’t quite understand, you know. So, there’s that education piece again.

At Moffitt Cancer Center, because we’re set up with to be different clinics depending upon the specialty, so we don’t have a navigator that comes through, but all the clinics have one, if not two pharmacists that are in the clinic, and when we’re talking to these patients and you’re having to consent them for oral therapies, if we think that the patient needs further understanding, especially because you consider the elderly, polypharmacy, who is not on five, six, seven, eight different drugs? We will ask the pharmacist to often help us step in and say hey, let’s take a look at all these meds, maybe we can clean something up and get rid of something. You know, that helps with the financial burden as well. And then we’ll reach out to whoever is prescribing that drug and say, you know, does this 80-year-old woman really need to be on Ativan® to sleep? Things like that because you’ll see these patients have several different providers, and so the medications come from across the board. If you can clean a few up, that does save them a few dollars per month, so again, I think the key point being that everybody is very important in that patient’s life with what role they play and everybody has something to contribute.
Lauren Berger:
I think one of the things that has come out key, you know, just in this discussion here is that communication. Communication with the patient from each of the healthcare team members is really critical because really you need to understand what that patient is going through. There are some patients obviously who would be really good in compliance and be able to follow things, others that the healthcare team realizes are a little bit more confused or don’t have such a good regimen or don’t have a good caregiver that can be supportive and help them. So, figuring out what the individual needs of a particular patient are is really critical.

Slide 24 - Myeloma Oral Adherence Information & Resources
One of the things that we talked about are some resources, so I’m happy to share a little bit about some resources that The Leukemia & Lymphoma Society has and then hopefully you might be able to share some ideas also. So, we’ve newly created a web page called Myeloma Oral Treatment Adherence. We will be creating more oral adherence. This one is a little more specific for myeloma, but it really is not only for because a lot of the information is really applicable to other diseases too. So, there’s a web page, which is right over here. And then I think the middle one is a calendar. So, it is about to come out. It’s a print calendar. It can be downloaded or we can mail it to patients or to healthcare professionals to share with your patients. So, it’s called a medication resource for myeloma patients.

Also, on the right, you see a fact sheet, so that just provides some highlights about what kinds of issues there are related to oral adherence, and a little bit about some strategies and things for patients that would be helpful to them in trying to remember the medication.

Slide 25 - The Leukemia & Lymphoma Society (LLS) Offers
We also have created a video called Oral Therapies and Myeloma Medication Adherence. While it’s specifically some tips related to myeloma, it’s certainly very applicable for patients. So, if you had a patient that was just newly on chemotherapy or a TKI or anything for any sort of disease where it’s oral, there is a physician, a nurse and a nurse practitioner and two patients talking about their experiences and what strategies were helpful to them in terms of remembering their medication. One of them mentions that, you know, at times he really does forget and he needs his wife, his caregiver, to really be that supportive person to make sure he’s on track, because, as
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

Cara Kondaki, LCSW, CBPN-IC, OSW-C
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Jennifer Powers, PharmD

May 3, 2016

Lauren Berger:
he admits, he says, “This is my lifeline. If I’m not taking these meds, you know, I’m not going to be around to really talk about it, so that’s most important.”

We also have patient education programs, in addition to the videos, that are telephone web programs, which is usually a physician and a social worker or a physician and a nurse, and an opportunity for question and answer, both live and submitting questions in advance. And then we archive all the programs on our website. An example of one of the videos is a CML video, The Role of PCR Testing, and you see a picture of a doctor there. So, the doctor is talking to a patient, and he needs to come in for his PCR testing and what the PCR testing means and how he needs to adhere to his oral meds and he may feel good, he is a CML patient and he feels good and he’s not having any issues, but if he gets his testing regularly and he’s communicating with his doctor, he knows that when he goes on vacation he knows that his numbers are good or maybe it’s not the right time for that. So, it’s really, once again, it’s the key of the communication.

Also, communication among healthcare professionals as you all mentioned. I think many hospitals are now forming teams where it’s various different healthcare professionals talking about the issue of oral adherence. Patients may be not coming into the hospital as often or seeing the doctor in the doctor’s office as often, but the issues still come up, and if everyone is not communicating as a team and it becomes a much, much bigger plan. I was in a session last week at ONS, and there was a whole team of nurses talking about what’s going on in each of their hospitals and how it seemed simple. You know, it’s oral adherence. It’s oral meds. It seems pretty simple. Just give the patient some instructions and all kinds of complications. Maybe the patient doesn’t take the meds as we talked about, but at times, the patient may have taken too many, got confused, thought they didn’t take it and took it, and ends up in the emergency room, and ends up as an inpatient and where are those kinds of issues.

So, you know, that kind of communication, and I think more and more that will be happening in hospitals and in outpatient clinics also where the team is really communicating with each other and seeing what the issues are.

Slide 26 - The Leukemia & Lymphoma Society (LLS) Offers
Lauren Berger:
The Leukemia & Lymphoma Society has an Information Resource Center, which individual oncology nurses, oncology social workers, and health educators. They speak
Lauren Berger:
individual with patients on a daily basis. Calls all day long, whether it’s information about a clinical trial, somebody is looking for some resources. We do individual clinical trial searches for a patient from the time they make the phone call just to get more information to looking for a trial. And then even contacting the PI, getting more information, helping that patient look for a trial and providing all the information until they’re actually enrolled, and we found that the numbers of people who call the Information Resource Center requesting information about a clinical trial and actually getting through and enrolling in a trial have greatly increased since we have dedicated people specifically doing that, working with the patient, whether it’s an hour, two hours, or following up at night and day further in the future. So, that’s really something.

So, if you have patients that maybe you don’t have the time or the nurse doesn’t have the time or the doctor doesn’t have the time to spend the time to look for a clinical trial for that patient, we’re happy to be a resource for that. We also have live online moderated chats moderated and facilitated by oncology social workers. And that gives people an opportunity to share experiences and concerns and so we have lots of different things online, as well as our chapters scattered throughout the country. So, please feel free to contact our Information Resource Center, they can be a resource for any different material, any different financial assistance, psychosocial support, and we’re happy to be of that service, and there is never a charge for anything that LLS does.

We also have a new online social network which has a separate section for healthcare professionals and one for patients in all the different disease states. So, it’s a new way that LLS is providing for patients to connect with each other, both to share questions, concerns, share information, and just strategize to be effective in taking their meds and also understanding the disease and treatment.

**Slide 27 - The Leukemia & Lymphoma Society (LLS) offers**
Also, professional education programs such as today’s. The one on the right you see was actually held last week at ONS, and it will be a virtual lecture online so those of you, most of you I’m sure are all busy during the day and hard to get to programs even when they’re held live, we always produce them as a virtual lecture afterwards and you can earn continuing education credit for that.
Improving Adherence to Oral Therapy for Cancer: The Role of the HCP

Cara Kondaki, LCSW, CBPN-IC, OSW-C
Lisa Nodzon, PhD, ARNP, AOCNP®
Jennifer Powers, PharmD
May 3, 2016

Lauren Berger:
Slide 28 - Question & Answer Session:
And then we thought we would just open up with any additional questions and to share some strategies perhaps that work in your hospital or your clinic that you work in for patients with helping them adhere to their meds.

Unknown Speaker:
So, prior to working with AbbVie, I was a heme social worker at the University of Chicago, and I love the idea of communication, and I started in 2005 and by the time I left a few years ago, I probably spent more time with the pharmacist than anyone. And it was especially like right before a patient was discharged, and I covered the bone marrow transplant unit. They were on a truckload of medications and they really helped clean it up, so I really like that comment. But I think one takeaway, too, if I was still in practice, is not just deal with that emergency and deal with getting them the medications, but taking it a step further and actually spending the time with the patient. So, this is the plan, and either doing it with the nurse or the pharmacist, but really taking it to that next level to try to prevent some of these things from happening.

Jennifer Powers, PharmD:
I think that goes back to the motivational interviewing as well and empowering patients and giving them back some piece of control in their treatment. I think any time we equip the patient with a piece of something that they can take part in is really important because it does give them a sense of something that they control in oftentimes what is uncontrollable. So, I think it’s very important to engage the patient on a regular cadence to see what elements and where they can play a part in controlling and self-managing, so I think that was a great point.

Lauren Berger:
Kind of meeting the patient where they’re at and figuring out what their needs are, what their concerns, and I know we were talking a lot in our planning before this session, is that so many patients are not necessarily going to tell you their concerns, but you’ll see it in various different ways and you need to be able to pick up on them and pick up on what’s going on and listen to the patient and meet them where they’re at, and whether it’s an app on a phone that works for them or a calendar that works for them if they’re not is tech savvy, or the pill boxes. There’s so many different kinds of things that are out there, and there will be more and more as people take more oral meds, but just to figure out what works for them.
Lisa Nodzon, PhD, ARNP, AOCNP®:
And I think that’s where everyone kind of plays that key piece because in practice our time is very limited. We have a lot of patients to see in clinic and we’ve got to get them through and get to get them to the infusion center for their IV chemotherapy or it’s an eight-hour infusion, so our time is very limited, so subtle cues that someone may pick up on a patient and be like something is wrong, something is wrong. But then making sure that that communication takes place even if it’s a hunch that you think something is wrong or “Hey, he said something a little strange the other day” or, “You know what, just found out this patient lost their job,”, but we didn’t hear that in clinic or maybe I heard it in clinic, and I reach out to the social worker and say, “Hey, you’ve never met this guy before, but he just lost his job. He hasn’t expressed to me that he has financial concerns, but maybe reach out to him.” Because the understanding is you’ve lost your job and you’re thinking here comes COBRA insurance and here comes everything else, and this patient is in the middle of therapy, so their ability to find a job is going to be very difficult, because who wants to hire a patient that can’t be at work five days a week. So, that becomes harder for that patient, so subtle cues, but under the short time that we have, because we know that patients with cancer are living longer, so there’s more of them. And there’s more of them but less of us, and we have less resources. You know, we have less time, which is always the key factor.

Cara Kondaki, LCSW:
And I think that’s where navigation can play a great role. Being a social worker navigator, it’s a little bit different because the doctors tell me it works great because I can get them on the phone to tell me what’s bothering them. Well, why don’t you just come in or, you know, get them to come in, let’s see what we can do to help you instead of them isolating themselves at home and deciding they’re not going to come back. As an advocate, sometimes we do have to send letters just saying, you know, we’ve called you, you haven’t come in. And I’ve had people come up to me, and go, you know, you were persistent and I could tell you cared, so I just came back. I’m like, well, I’m glad you’re here, and I’ll give them a big hug and I’m like, “Now let’s see what we can do to help you.” So, I think it is really important and social workers do play an important role even in the navigation process of getting people to follow-up with the healthcare providers or the nurse or the doctor and even financially say but you know there are things we can do to help you with this, so just come in and let us talk to you.

Lauren Berger:
Thank you very much for coming.