

TRANSCRIPT
**Nursing Management of Challenging Side Effects:
Case Studies for Hematologic and Other Cancers**

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Nursing Management of Challenging Side Effects – Case Studies for Hematologic and Other Cancers

Clare Karten:

Welcome, everybody. I'm Clare Karten, Senior Director of Mission Education at The Leukemia & Lymphoma Society. And it's my pleasure to thank you for joining us at our symposium, *Nursing Management of Challenging Side Effects: Case Studies for Hematologic and Other Cancers*.

The Leukemia & Lymphoma Society is committed to providing you with the most up-to-date information about blood cancers and providing patients and families with comprehensive information and support. That includes information about treatment options, decision-making and clinical trials. Among our patient services, we have programs for education; we have local and online support groups. As well, we have co-pay assistance and financial aid programs and many other services. And you know that we're committed to research. LLS has awarded more than \$800 million in research funding since 1954. And through our public policy initiatives we are working towards a future where all patients have access to the best treatments available. We know that we share a sense of urgency with all of you.

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Disclaimer

I would like to acknowledge the Centers for Disease Control and Prevention for helping to support our symposium. And thank you to our speakers, Kate Breitenbach, Eric Cohen, Kathy Daily and Carol White, for presenting today.

Their presentations will be followed by an important question and answer and discussion session.

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Case Study: Unlocking the Complexities of Nursing Management of Aggressive Lymphoma in the Elderly

Now I'm honored to introduce our speakers who will share their strategies for managing some of the challenging side effects of cancer and cancer treatment with you.

Our first two speakers, Carol White and Kate Breitenbach, will present *Unlocking the Complexities of Nursing Management of Aggressive Lymphoma in the Elderly*. Carol is an advanced practice nurse and Kate is a clinical research nurse, both in hematology/oncology at the University of Chicago Medical Center.

Carol and Kate.

Carol White:

Good afternoon and thank you for joining us.

Kate and I are privileged to care for patients and families diagnosed with leukemias and Burkitt's lymphoma. I work on the inpatient unit as the advanced practice nurse for the leukemia service and Kate is the clinical research nurse for this patient population. To mirror what we do in real life, we'll be going back and forth throughout this case study, pointing out both the inpatient and outpatient aspects of care.

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The Beginning

When you look at our patient chosen for this case study, it seems that he really doesn't fit the definition of a minority or the underserved: a 72 year old white male with insurance. However, what Kate and I would like to discuss throughout this entire case presentation is the fact that our elderly actually are quite underserved when it comes to treatment options and particularly for clinical trials.

Ron, a 72 year old gentleman, was diagnosed in late August with lymphoma by a local physician. It was prior to a holiday weekend so Ron was given a steroid, Decadron[®] to take, with the plan to then return on Monday to start his chemotherapy treatment.

His past medical history was notable for diet-controlled diabetes, hypertension controlled with a single agent antihypertensive, and a remote history of prostate cancer treated with prostatectomy, adjuvant therapy and radiation.

Ron was brought to the physician's office by his significant other, Mary, who was his girlfriend. Ron had been married for 49 years and per his sister's description, had the dream marriage. When his wife died suddenly, Ron was devastated but within a year began dating Mary, a longtime family friend. Overtime, we considered Mary to be his wife as much as both she and Ron did. When she brought Ron to the doctor he was very lethargic, was having trouble walking and was experiencing periods of confusions. As soon as the doctor examined Ron, he admitted him to their local hospital. Radiographic and lab tests revealed massive lymphadenopathy, acute renal failure with a creatinine of 7, hypoxia with an O2 saturation of 86 percent. Blood cultures were drawn and were found to be positive for *Klebsiella pneumoniae* along with *E. coli* UTI.

When all of the test results came back, based on Ron's age, co-morbid conditions and the aggressive lymphoma, the physician recommended that Ron and the family consider hospice and also change his code status to DNR/DNI. On the surface when you look at these statistics, that doesn't seem like a bizarre option for Ron.

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Karnofsky Performance Status

However, one of the things that we really need to consider, is what is a patient's performance status, both as they present with the diagnosis of cancer and their pre-diagnosis performance status. (I'm going to skip ahead to the performance status slides.)

The two scales that I think we're most familiar with in nursing is the Karnofsky Performance Status, which starts with the best status at 100 percent, and death at zero.

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Eastern Cooperative Oncology Group

I personally like the ECOG performance status. It's just simpler and it's cleaner as far as

how we assess our patients. But whether you use either of these performance statuses, we can see that Ron was definitely at 3 or 4 and at the 20% to 30% on the Karnofsky.

However, one of the things that the family said is that Ron's performance status prior to this weekend and the diagnosis of his lymphoma was a zero on the ECOG or 100 percent on the Karnofsky, which denotes an excellent performance status. They felt that Ron deserved a chance to have another treatment option, thus they were transferred to the University of Chicago.

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Facts/Nursing Plan of Care

Upon Ron's transfer to the University of Chicago, we assessed Ron's present symptoms. Although he presented with periods of confusion at the outside hospital, he was alert and oriented times 3 and was actually aware when he became confused. He was fatigued and weak. He needed two assists to get in and out of bed, but was able to stand on his own and walk with assistance. His blood count revealed a white count of 30,000 with more than 60 percent circulating peripheral blasts. His LDH was 8,500. For those of you who work in solid tumors and don't deal much with an LDH (lactate dehydrogenase) one of its functions is as a marker for cell breakdown. Normal levels are between 110 to 240. So we can see that Ron has massive apoptosis or natural cell death going on just from the rapid proliferation of his cells and the decadron that had been given previously.

His uric acid was 5.5. Remarkably, however, we found that his creatinine was 1.1. At the previous hospital they had started allopurinol and fluids to try to reverse the acute renal failure. It had obviously worked!

On physical exam it was noted that he had massive bilateral lower extremity edema, left upper extremity edema and left cervical lymphadenopathy. To give you an image: I'm told there's lots of baseball fans here, so picture a baseball in the left side of his neck and that was the size of the adenopathy that we saw on presentation. He also had sutures in his left chest wall from a cutaneous nodule that had been biopsied at the outside hospital.

So from a nursing perspective, when we're presented with this patient, it might be change of shift, you might be short-staffed that day, so what are the priorities that are needed to ensure that we get Ron safely tucked in before we start all the diagnostic testing?

Our staff immediately initiated fall precautions to ensure Ron's safety. We also needed to have close monitoring of his fluid status, as he had received liters of fluids when he was at the outside hospital. Particularly with the elderly, if there's an inability to process these fluids, it's very easy to see pulmonary edema develop. With that in mind, we made sure that we had scheduled oxygen saturations and also that we continued the IV antibiotics that had been prescribed at the outside hospital.

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Facts/Medical Plan of Care

To complete the diagnostic work-up, we did CT scans and found the bulky lymphadenopathy that had been reported from the outside hospital. There was also involvement of his left iliac and retroperitoneal lymph nodes, along with massive hepatosplenomegaly.

As is protocol at our hospital, and I'm sure at many of yours, we repeated the bone marrow because even though we had the slides, we wanted to make sure that the outside diagnosis

was correct. Lymphomas can often be difficult to diagnose, and treatment differs according to the diagnosis and prognosis. We are fortunate at University at Chicago that our hemapathologists actually are the authors of the World Health Organization prognostic and diagnostic manual for hematologic malignancies. So when our doctors give us a diagnosis, we move forward with treatment quickly.

What they came back with was a diagnosis of a B-cell lymphoma, but not a Burkitt's lymphoma as diagnosed at the outside hospital. It was an unclassifiable B-cell lymphoma as it had markers that were indeterminate between a diffuse large B-cell lymphoma and a Burkitt's lymphoma. In the old days we called this Burkitt-like lymphoma, but now the new terminology is either double hit or large diffuse B-cell unclassified.

I just happened to pick up and thumb through my *Clinical Journal of Oncology Nursing* for April and there's an excellent review article on B-cell lymphomas, unclassified. However, we don't have to wait until we read the article as Kate will now tell us a little bit about double hit lymphomas, along with what are the special considerations that we needed to be aware of before we started aggressive treatment of this elderly patient.

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What is Double Hit Lymphoma?

Kate Breitenbach:

Ron is diagnosed with double hit lymphoma. What does double hit mean? Double hit lymphoma is a mature B-cell neoplasm and it's termed double hit because of two different cytogenetic abnormalities.

Double hit lymphomas are categorized by the translocation of both the MYC and the BCL 2 gene. Translocation of the MYC gene, as Carol mentioned, is a characteristic of Burkitt lymphoma. And this cytogenetic abnormality facilitates increased cellular proliferation. To further compound the aggressiveness of this malignancy, another translocation of the BCL 2 gene is present. And this gene is responsible for inhibition of apoptosis or programmed cell death. So you can see how the combination of increased cellular proliferation and inhibition of apoptosis will lead to an extremely proliferative and aggressive neoplasm.

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Clinical Features and Karyotype of Dual-Hit Lymphoma/Leukemia

Tomita and colleagues, a Japanese group, did a case analysis of 27 cytogenetically proven cases of double hit lymphoma to help characterize this malignancy. And this table from their article shows the demographics and clinical presentation of double hit lymphomas in comparison to other aggressive leukemia and lymphomas. And the third column, this is a hard slide to look at, I apologize, the third column from the right is what we want to focus on.

You can see that there's a relatively equal presentation between genders with this type of lymphoma. And the age range at diagnosis is quite a span. It's 36 to 79 years with the median age being 51.

It's not surprising, considering the aggressiveness of this lymphoma that the majority of cases presented at a later stage, in either stage 3 or stage 4. This disease does not always involve the bone marrow. However, the majority of patients have marked extramedullary disease.

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Overall Survival of 27 Cases of DHL

These same 27 patients are plotted on this survival curve and we can see that not only is this a very aggressive lymphoma, it's also very difficult to treat, with the median survival being six months and only 22 percent of patients being alive at one year.

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Cancer in the Elderly

Working in healthcare we're very aware that our population is aging and people greater than 65 years of age are currently the fastest growing segment in our society today. By the year 2030 one-fifth of our population is going to be older than 65 years. And we know that cancer also increases as we age. And 50 percent of new cancer diagnoses will occur in someone over the age of 65. Despite this increased incidence of cancer in the elderly, really minimal oncology research has been done to focus on geriatrics. And when they are included on clinical trials, the eligibility criteria is quite rigid and it makes it difficult to kind of expand that data to the population at large. These statistics point to an immense need for us as oncology care providers to be aware of the special needs that this group have and to supply them with tailored healthcare.

Ron was transferred to the University of Chicago after the diagnosis of lymphoma was made at an outside hospital. Both he and his partner Mary were frustrated to hear that their local oncologist had recommended hospice and did not think that there was any treatment for his malignancy. He came to us seeking a second opinion.

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Chemotherapy: Challenges Specific to Elderly Patients

Treatment of cancer in the elderly with chemotherapy and other modalities is challenging for a multitude of reasons. Co-morbidities such as hypertension, cardiac disease, GI illness and anemia associated with aging make it difficult to manage patients who may have an exacerbation of these conditions with treatment.

Additionally, patients with severe co-morbid conditions, whose life expectancy is less than one year, may not be appropriate candidates for chemotherapy, since the risks may outweigh any benefit.

It's also important to take into consideration in our elderly population age-related organ function decline. Changes in body fat and water composition, as well as decreases in their liver and kidney function, all change the metabolism, distribution and absorption of drugs. Their bone marrow reserve is decreased, which we know with chemotherapy will cause pancytopenia and this can be prolonged in the elderly, putting them, already a vulnerable population, at an increased risk for infection.

Coronary artery disease that is associated with normal aging, in addition to cardiac conditions, may exacerbate cardiac toxicity with certain chemotherapies. Specifically anthracyclines should be used with caution in the elderly and a cardiac work-up should be done ahead of time to clear at-risk patients before they get this type of treatment.

Lastly, evaluation of medication should be done at every patient encounter to check for drug interactions and assess for side effects. When I spent time in a geriatric clinic I was shocked by the patients that would come in on multiple medications, sometimes two for the same

treatment, and this is polypharmacy, which is defined as too many medications than are clinically indicated and multiple medications for the same condition. So if you're discharging a patient or if you're seeing them in clinic, make sure you're asking them what they're taking. If possible, you can ask them to bring their meds in, though they'll often forget. And ask them how they're taking them.

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Cancer Treatment in the Elderly

In addition to asking patients about medications, we should be performing a comprehensive assessment that's tailored to the senior patient. Because chronological age does not always correlate with a person's physiologic impairment, our assessment should include not only co-morbid conditions, but their functional status to better evaluate a patient's ability to tolerate cancer therapies.

This table is taken from Up-to-Date and it shows the various domains that we should be assessing for in our elder patients.

Carol mentioned the performance status scales earlier. In addition to functional status, we should be asking patients about their activities of daily living. Are they cooking for themselves, do they dress and bathe themselves? Independent activities of daily living, we should also be asking about. Who pays their bills and does their finances, are they still driving? These may be the first deficits that we see in a cognitively impaired patient.

And we also want to ask them about their social support. Who do they have at home to help them? A lot of our elders live alone, so it's something we want to be asking about when they go through this treatment.

We also want to know what their nutrition is and you can measure their BMI in clinic.

We need to evaluate their mobility and their gait. Ask them to walk for you. Do they use assistive devices, are they able to get around? Are they having problems with their memory and cognitive deficits? Are they depressed or are they worried?

All of these domains play a role in the elderly person's outcomes with cancer treatment. And when we evaluate Ron's performance, as Carol mentioned, he's a pretty good candidate for treatment. However, we have a lot of frail elders who are not such good candidates.

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Characteristics

Carol White:

So to pick up with Ron, before we could really give him any treatment, we needed to assess what were the presenting signs that might put him at risk for developing acute end organ failure. We also needed to consider if there was anything to be done prior to start of treatment to prevent any toxic occurrences. We wanted to avoid a trip to the MICU at all costs. Ron had presented at the outside hospital in renal failure after receiving Decadron[®] in a dose that was suppose to gently debulk his tumor. This put him at great risk for tumor lysis syndrome. So who is at risk: patients who have a rapidly proliferating tumor that is known to be sensitive to chemotherapy treatment, who present with a large tumor burden, seen either with elevated LDH and/or a high white count. So our patients with acute leukemias and large diffuse B cell lymphomas are most at risk for this condition.

What you may see clinically is nausea, vomiting, diarrhea. Patients can present with lethargic, confused, seizures or even cardiac arrest.

So why does this occur? Tumor lysis is considered an oncologic emergency. Due to the breakdown or the lysis of these cancer cells, elements such as potassium, phosphorus, calcium, nucleic acids are dumped into the circulation where there can be a buildup of uric acid crystals, leading to hyperuricemia and to renal failure. In the same manner, calcium and phosphate binders precipitate and can contribute or cause renal failure as well as cardiac events.

As we said, Ron was definitely at risk, so for the medical and the nursing team, the most important thing we could do was prevent this from occurring.

The recommendation of fluids for tumor lysis syndrome is two to three liters per meter squared a day. Our interns take that literally and oftentimes our elderly patients are on 200 to 300 cc's an hour of fluids. Sometimes we have to ask them to reconsider the fact that our elderly patients can be at higher risk for fluid overload. So nursing assessment of respiratory and kidney function and cardiac function are extremely important.

Along with the fluids, oftentimes diuretics are needed. I worked with a physician who called it the push-pull method of fluid management. So that we will push the fluids in and we're going to give Lasix[®] to pull the fluids out.

The other important piece with the management of tumor lysis is to try to prevent the uric acid crystals from accumulating in the circulation. The standard of care has always been allopurinol until our pediatric colleagues clinical trialed rasburicase, which now is used routinely for our patients who are assessed at high risk. The ability of this drug to degradate the uric acid to a very soluble form of allantoin eliminates the potential for this crystal buildup in the kidneys.

Finally, these patients are at risk of going into tumor lysis quite rapidly, so oftentimes we have labs drawn every four hours, sometimes every six hours. This can be the biggest challenge for nursing, if you get a patient in who is critically ill and doesn't have a central line yet and has peripheral edema from all the fluids. However, early recognition and management of tumor lysis may save the patient from a trip to the MICU and /or dialysis

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Characteristics

Kate already spoke briefly about how the physiological reserve of the kidneys of the elderly are compromised, so over time Ron would be monitored very closely in an attempt to avoid dialysis. For our elderly patients who have to go on dialysis, who go to the intensive care unit, we know the morbidity and mortality are quite high.

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Characteristics

Ron was also at risk for respiratory compromise. Although all of the things mentioned on the slide are of importance, the most important assessment when he came in was to examine his left cervical lymphadenopathy to determine if there was any external compromise of the airway. Was there a shift in his trachea from the midline? Examining the oral cavity, was there any internal compromise, any swelling or occlusive at the back of the throat? Of utmost importance is good lung exam, auscultating to assess for stridor or decreased lung sounds.

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Characteristics

Mental status changes had been reported at the outside hospital and we also had evidence of periods of confusion. Of all the things that we can assess for, one important thing is what is your patient's baseline mental status. I recently had a patient come in, a little gentleman in his eighties, that everyone said was just fine, he got along fine at home. When we assessed this gentleman, we found him to be experiencing dementia and so our treatment course changed abruptly.

We had already had reports from Ron's family that his baseline mental status was alert, oriented, active. So what contributed most to Ron's mental status changes was the involvement of the central nervous system with his lymphoma. This can be a common sanctuary site with high grade lymphomas as well as leukemias. It is reported in the literature, if patients are not treated at diagnosis (even if they don't present with CNS disease), 40% to 50% of these patients will develop it over time. So it was important for us to initiate aggressive intrathecal treatment.

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Characteristics

And finally, Ron came to us with a diagnosis of infection. He had a *Klebsiella* and an *E. coli* UTI. It was important for us to continue or change IV antibiotics to match his correct and potential infection profile. The lymphoma itself will put him at risk for more opportunistic infections. Immobility can contribute to infections, particularly pneumonias. Physical therapy was ordered to come in as often as they could to work with Ron, to mobilize him and keep his lungs expanded.

And finally with the initiation of chemotherapy, we knew that we were going to cause a prolonged neutropenic phase, so filgrastim or Neupogen[®] was included in the treatment plan to decrease the neutropenic phase.

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Treatment Plan

When considering a treatment plan for Ron, one of the most important things, as Kate mentioned, is to determine who are your fit elderly and who are your frail. On presentation we would think Ron was our frail elderly. But the team felt that his baseline activity and performance status would allow us to treat Ron. One of the things we needed to do was assess his cardiac status, which we did with a MUGA scan. He had greater than a 50 percent left ejection fraction, he had no wall motion abnormalities, no stenosis, no regurgitation. His creatinine and his kidney function had returned to a baseline that was safe to treat. His liver function tests were all within normal limits.

The plan to start treatment was discussed with Mary and Ron to determine if he wanted to receive this aggressive treatment,. They were told there was no guarantee of a successful outcome, but our goal was to cure him and return him to his previous functional status. They chose to go ahead with the treatment. In determining the treatment plan, there is no standard of care for this lymphoma and there are no clinical trials for patients at this age. We looked at our choices that knowing the plan needed to include multiple drugs given sequentially over a period of six to eight months. Hyper-CVAD with Rituxan[®] and intrathecal chemotherapy is what was

chosen.

For brevity of time, since this is not a chemotherapy talk, I'm not going to go into the specifics of each drug in the treatment plan. But what I will say, if you look up the drugs that are included in Hyper-CVAD and look to any kind of guidelines for the elderly, you will find none. There's only a disclaimer that says use with caution. And so that's what we did.

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Discharge Plan

Ron actually survived our chemotherapy and five weeks in the hospital, and his counts started to recover. At that point we wanted to send him to an acute rehab placement near his home. Unfortunately, his insurance and the place we picked had some issues. And again, I won't go into all those issues, but over time he recovered enough to be able to go home with home physical therapy.

The next issue, of course, was the fact that everyone assumed that Ron had drug coverage because he had Medicare and he had a supplement. However, he had never taken Part D because he was a veteran and he got his drugs from the VA. Because he didn't have a hematologist there, Ron was unable to get those drugs. So again, we had to be creative and think of what were the generic things and what were the absolutes that Ron needed to take at home.

We also contacted the local physician who had sent Ron to us and asked if he would follow him, at which point we discharged Ron and I handed off all those problems to Kate.

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Out-Patient Management

Kate Breitenbach:

So like many of our patients, Ron traveled quite a distance to get care at our academic medical center. If you're familiar with Chicago, he came from outside of Rockford, so it was a little over 100 miles, and anywhere from two to four hours, depending on if they got lucky with traffic.

Carol mentioned part of his discharge planning included his local oncologist who assessed him for toxicities at least weekly. We also employed a home care agency to draw labs at home, so that we could transfuse him locally when he was at his nadir. And part of my job was to kind of coordinate the care of all this, be in communication with our care team, the local oncologist, the home care agency, to make sure everyone was on the same page with managing his illness and the side effects.

I really believe that an interdisciplinary team approach like this one provides our patients with the best quality of care when you have multiple input from people in all different backgrounds of healthcare.

In the outpatient setting, like Carol mentioned, we manage a lot of side effects with his therapy. Aggressive chemotherapy had given Ron significant fatigue, it had decreased his mobility and had a lot of proximal muscle weakness. This was due to neuropathies as well as some urinary incontinence issues. And he also struggled with depression and how to cope with such a life-changing illness.

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Management of Fatigue: Evidence Based Care

Cancer-related fatigue is the number one complaint that I hear from patients, either during treatment or even into survivorship. And it's routinely identified by patients as one of the most distressing symptoms related to their cancer treatment. It diminishes their quality of life and unfortunately we overlook assessing for this in our clinics and in the hospital, and so therefore it's under-treated.

It's important when you're assessing for fatigue to first consider any underlying medical conditions the patient might have. Should be looking at their blood counts, what their hemoglobin is, are they anemic or are they depressed. Anemia is easily treated with transfusions and growth factor support. We'll talk a little bit more about managing depression later. But managing depression and pain can also help to alleviate fatigue in patients who have that underlying medical etiology.

Whenever patients complain about fatigue, I ask them how active they are at home and whether or not they're exercising. Because the only research that shows an improvement in cancer-related fatigue is exercise and resistance training. So even though you patients are going to have a really hard time believing you when they come to clinic tired and you're telling them to exercise, it's still important to nag them and encourage them to get up in the morning, to shower, get dressed and start exercising slowly.

A referral for physical therapy can be helpful, to get another person onboard, so the patient has someone scheduled to come in and help them with their activities and learning new exercise. And this is what we did with Ron, though he frequently rescheduled his physical therapy appointments and wasn't very interested in getting exercise care.

Other treatments that you can consider are complementary therapies. A study with yoga in cancer survivors has shown to improve their energy.

And just briefly I want to mention the use of stimulants and corticosteroids because their use is a little controversial. The research on clinical trials with fatigue reduction and the use of steroids or stimulants is very varied. And I've seen this used only in our palliative care program. So these are for patients who are very severely fatigued. So long term treatment of fatigue should not be done with stimulants and corticosteroids, due to their unknown efficacy and the risk for side effects.

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Depression in the Elderly

Depression in the elderly population is huge and it's increased in the context of a life-threatening illness such as cancer. I don't think that we incorporate the assessment for mental illness enough into our encounters with patients, nor do we accurately screen them or treat them for depression. And as a result the mental illness remains under-diagnosed and inadequately treated. And in the elderly it can be a little difficult to assess for this because often when they present, they present with atypical symptoms or physical impairments.

Being depressed or worried is not a normal consequence of aging and it can cause unnecessary suffering, impaired functioning, increased mortality and excessive use of our healthcare resources.

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Depression in the Elderly

So when you're seeing patients, evaluating for depression can be done with some very quick and straightforward questions. I usually start by reaffirming what the patient is going through and asking them how they're coping with all of this. Additionally you can ask them if in the last month they've been feeling down or depressed. And an especially sensitive question for the elderly when evaluating is whether they've stopped doing activities they previously enjoyed. Positive response to any of the latter prompts a more formal screening and any of the instruments on this slide are valid tools, though I prefer to use the Geriatric Depression Scale.

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Treatment Options

This slide just shows you a variety of other treatment options that you could use with your management of depression in patients.

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Pharmacological Treatment

And if you do decide to choose pharmacologic treatments, selecting an antidepressant is really based on the side effect profile that the patient is complaining about. SSRIs are the first-line therapy for treatment of depression and they're usually well tolerated. Fortunately there are a multitude to choose from, so again, looking for one whose side effect profile counteracts some of the symptoms that a patient is experiencing is the best way to select which medications to choose.

Our geriatric oncologists really like to use mirtazapine or Remeron[®] because in addition to improving a patient's mood, it also stimulates their appetite. And taken at night it can help them sleep.

Duloxetine and bupropion are two other medications that are kind of atypical agents that you could consider using if someone is having a lot of neuropathic pain or if they want some assistance with tobacco cessation.

And in Ron's case we chose to use Lexapro[®], an SSRI, for the treatment of his depression, and we saw an improvement in his symptoms over the course of the next several months.

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The Middle

Carol White:

In the interest of time and our next speakers, I am going to go through this some of these slides quickly.

So over the next two to six months Ron came in and all of the symptoms that are listed here actually increased. The only one that really didn't, as Kate mentioned, is his depression, and he really did seem to respond well to the Lexapro.

The last cycle, Mary asked me to come out in the hallway, and she said, "Ron's embarrassed to tell you, but he's having really much more frequent urinary incontinence." He'd experienced this in the past with his prostatectomy. So we called the urology consult who came, did their exam, did their tests and then said that Ron had an incompetent sphincter and that surgery was the remedy, which, of course, Ron could not handle. Consequently we got very creative again and used a Texas catheter, which Ron wasn't happy about, but he agreed to it... and

he was okay with it in the end.

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Psychosocial Issues

About two weeks after we had completed his last cycle of chemotherapy, Ron was brought back into the hospital much weaker, having much more incontinence. He was at the nadir from his chemotherapy, his platelet count was 1,000, and he had been scheduled with his local doctor to get his transfusion, but was admitted to U of C instead. We did a work-up, we did not find any metastatic disease on MRI, but there were degenerative changes in his spine. We did an EMG which showed what we had all figured was happening, that he had proximal muscle weakness, most likely from his steroids, and peripheral neuropathies from the vincristine chemotherapy. We did an LP, importantly that was negative. Consequently, we spoke with Ron and Mary about the fact that maybe this was just the accumulation of all of this chemotherapy over the six to seven months, and what was their focus.

Their focus then was quality of life and they decided that perhaps acute rehab would be a great benefit to Ron, so that he could come regain his strength and become active again. He was able this time to move on to acute rehab.

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Changing Goals of Care

Kate Breitenbach:

So as Carol mentioned, we started to kind of change our direction with Ron and discuss what his future goals of care might be.

And it's important when you're going to engage in these discussions with patients, you identify who their main support is and try and get all of them together when you're having family meetings to talk about changing goals of care.

So for Ron, his main support included his partner Mary, his sister Nan, and his two adult sons.

These discussions can also include discussing DNR-DNI and power of attorney and it's helpful to do this before the situations become imminent.

Frequently when rounding on clinical patients, I've seen the medical team asking the patient, do you want everything done? What does everything mean? Of course, when we fail to explain the complexities of what we can do to sustain life, the response from a lot of patients is why do we ask, of course do everything. These types of conversations really need to be given the time, so we can explain what it might mean if you can't breathe on your own or if your heart stopped beating, would you want us to do chest compressions to bring you back to life. Or if you were unconscious and couldn't communicate your wishes, what would you want us to do.

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What are R's Future Goals of Care

Both Ron and Mary agreed that they did not want further chemotherapy after he finished his prescribed six cycles. And though we were still treating Ron with a curative intent, we knew that in the majority of patients who are diagnosed with double hit lymphoma, that the disease would eventually relapse, and our focus began to shift towards increasing Ron's quality of life

and helping to alleviate some of the side effects from the chemotherapy we had caused.

Though we had not put a name on it, what we are now implementing was palliative care. And palliative medicine is relatively new. It's just become more prevalent really in the last ten years. One article that I really like is a New England Journal of Medicine article that was published in 2010 by Temel and colleagues. And it randomized newly diagnosed non-small lung cancer patients who received palliative care, plus standard of care at the first encounter in the oncology clinic, versus standard oncology care alone. And of the 107 evaluable subjects, the authors found a statistically significant increase in the quality of life, fewer depressive symptoms and longer survival in patients randomized to receive palliative care, alongside treatment for their lung cancer. And this study really is highlighting the guidelines of the National Consensus Project for Palliative Care in the National Cancer Center Networks and the American Society of Clinical Oncologists, which is early onset of palliative care in conjunction with cancer treatment.

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What is Palliative Medicine?

So what exactly is palliative care? Though we say that we know and we understand what this means, it's really difficult to articulate it to patients and their families when they have questions. So at its very essence it's symptom management and aims to relieve suffering and improve patients' quality of life. And includes a multitude of providers and resources that can assist both in the medical management of symptoms like pain and fatigue, as well as social services. And it can help to facilitate and incorporate psychosocial and spiritual care into a patient's treatment. And it's not just treating the patient, but supporting the family and affirming their life.

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Other Frequently Asked Questions About Palliative Medicine

Patients frequently have questions about what palliative care is and I think the major one being does this mean that I'm dying. I think people hear palliative care and find it to be synonymous with hospice, when really they're two very distinct entities. Palliative care does not mean that the patient is dying. It also does not mean that we need to stop treatment. Patients can continue to receive chemotherapy; they can get dialysis and transfusions as well as all of their medical care, while still receiving palliative care services. Unlike hospice, there's not a prognosis of less than six months to their life to be eligible for this care. However, it can assist to the transition of hospice when that becomes appropriate. And many private insurers, Medicaid and Medicare, all cover some or all of the palliative care services. And the benefits for patients who receive care are immense. It helps to relieve pain and suffering, it assists them in making difficult treatment decisions, helps patients complete their prescribed therapies through symptom management, and it increases patient and family satisfaction. And it decreases costs associated with less hospitalizations.

This is really something that I wish we had initiated much earlier in the course for Ron and his disease.

Slide 34

The Beginning...Again

Carol White:

Ron was in rehab for two to three weeks and about a week after rehab he was supposed to return to the physician for an outpatient visit. However, Mary called and said Ron was lethargic, confused and was hardly able to walk.

Our doctor had Mary bring Ron into the hospital where we were going to reevaluate his disease status. It took four of us to get him into bed. He was incontinent of stool and of urine. When Mary said to him, "Ron, do you know who that is?" he looked up, opened his eyes and said, "Of course, it's Carol." So at least I felt like he had some orientation at that point.

While the staff was cleaning Ron up, I asked Mary and his son to step out in the hallway. Mary had told me that when she called the doctor, the doctor said if this is relapse or his disease return, we will probably be discussing hospice, so Mary was prepared. I think his son was prepared, but not quite as much. We had a discussion about what would Ron want right now, while we're trying to get him comfortable, while we're trying to control things. And as Kate mentioned, they said no, he never wanted to be on a ventilator. So we made him a DNR-DNI.

We started some fluids. His LDH, without anything, was 10,000. His uric acid was 17, so we gave him some rasburicase. We scheduled a lumbar puncture with chemo for the next day. The LP was positive with a significant number of lymphoma cells present; his disease had returned. The doctor and I went in to speak with the family and with Ron about what we did next. The doctor took his hand and said, "Ron, you fought as hard as you could and we've done everything we can, now we want to support you in whatever way you want us to, to make you comfortable." Ron looked at both of us and said "I am 73 years old and have had a beautiful life and beautiful friends. It's okay."

Ron and his family determined that they would want to go home with hospice and so that became our goal.

When we think about Ron and his caregiver, I kind of skipped past the caregiver fatigue because we're way over time, but one thing I'd like to mention. In *ONS Connect* last week, very interesting, I read this little tiny paragraph that said that there's a 22 percent report of post-traumatic stress syndrome in caregivers whose patients die in the ICU and there's a 4 percent PTSD for caregivers whose patients die at home. We also don't have time to discuss nurses' stress level either, but I can tell you my stress level was decreased significantly as we honored Ron's wishes.

What we did for Ron and Mary was to provide them with the ability to die as he wanted to. He was home for about ten days. Mary called me to tell me he was in a bed in front of a window looking out over a garden, that he had a good appetite, was eating anything he wanted to when he wanted to, and had all his family and friends come in and see him.

Slide 35

How Do We Take Care of Ourselves?

When I look at our case study I can say that Ron has touched my heart and Kate's heart in many ways. But most importantly, he gave back to us the commitment of what we do every day, which is to advocate for the patient. We can't stop the dying process, but we can provide patients with the chance to die with dignity, surrounded by the people they love.

Thank you.

Clare Karten:

Thank you so much for that presentation, which reflects your knowledge, your experience and your compassion.

Slide 36

Myeloma Case Study: Looking Beyond the Symptoms

And now I'd like to introduce Kathy Daily and Eric Cohen, who will present their *Myeloma Case Study: Looking Beyond the Symptoms*. Kathy is the multiple myeloma bone marrow transplant coordinator and primary nurse at H. Lee Moffitt Cancer Center and Research Institute in Florida. And Eric is Program Manager of Patient and Family Education at Life with Cancer, Inova Health System in Virginia. Kathy and Eric.

Kathy Daily:

Just yesterday myeloma patients were living only three to five years. And today many myeloma patients are living eight to ten years or ever longer. With longer survival comes challenges with treatment side effects and quality of life.

Slide 37

Disease and Treatment History

This is a story about Mr. Baxter, a 59 year old lawyer, who was a long-term myeloma survivor.

Mr. Baxter was playing racquetball when he noticed severe pain in his right rib. It was persistent and it became chronic, so he went to his primary doctor and they did X-rays. On the X-rays they saw that there were lytic lesions. Now his primary doctor knew that lytic lesions were a hallmark of multiple myeloma, so he sent Mr. Baxter to a hematologist. There, further work-up was done with labs, 24-hour urine, complete bone X-rays and a bone marrow biopsy. And in 2002 Mr. Baxter was diagnosed with IgG kappa myeloma, stage 3A.

Now Mr. Baxter had a history of anxiety and with the diagnosis of myeloma, you can imagine how it was exacerbated. Not only that, but he became depressed, he couldn't sleep, so now he has fatigue, he can't concentrate or focus at work, and he lost his job. And when he lost his job he lost his health insurance. And because he had a new diagnosis of cancer, he couldn't get health insurance on his wife's policy.

Now Mr. Baxter has gone from a two income to a one income family and he has no health insurance. His anxiety was sky high.

At this time his mother was also very ill and he couldn't help her physically, he couldn't help her financially and he could barely support her emotionally because he was so wrapped up in his own disease. So Mr. Baxter, on top of all of this, was having problems with his ex-wife and his two children from his previous marriage. So when we met him, he had rapid, pressured, repetitious speech. He would ask us questions and then answer them himself. We could barely get a word in edgewise. But we did recommend that he get VAD chemotherapy. And in 2002 this was standard of care for multiple myeloma: vincristine, Adriamycin® and dexamethasone. We also recommended that he get monthly bisphosphonates to strengthen his bones.

Now Mr. Baxter had three cycles of VAD and he responded very well. So we told him he

should have a total of four, go on to stem cell transplant, or have a total of six cycles of VAD, relapse and then go on to transplant. But he said no, he would have none of this. He was in remission, he wanted to see how it would go. We told him his disease would come back very quickly if he chose this. But he chose it anyway. And he relapsed.

Slide 38

Disease and Treatment History

So at first relapse we did high dose chemotherapy with melphalan and stem cell rescue. And once again Mr. Baxter had a very good response. But his sleep disturbance persisted, so his fatigue persisted. He also developed sexual dysfunction at that time, possibly related to the high dose melphalan, but more than likely multifactorial.

Now Mr. Baxter would bring us in articles from the web that he was surfing, he would ask us to critique them and tell him how they would benefit him. He was focused on his myeloma labs, he wanted the numbers over and over again. Mr. Baxter's anxiety was so high that we referred him to a local psychiatrist. And what do you know? Much to our surprise, he went. But only once.

So now Mr. Baxter, after five years of remission, had a second relapse. We treated him with thalidomide and dexamethasone, which was standard treatment for myeloma at that time. He continued to have financial problems, so we referred him to the Celgene assistance program.

After a few cycles, he complained of peripheral neuropathy. Standard of care would be to hold the thalidomide, wait until the peripheral neuropathy resolves or improves, and then start him back at the next lowest dose. Since myeloma is a drug-resistant disease, we want to maximize the benefit of every single treatment option we have. But no, Mr. Baxter didn't want that. Once again he wanted to do it his way, even though we cautioned him that the disease would probably come back quickly if he didn't continue the thalidomide.

Slide 39

Disease and Treatment History

Guess what? Mr. Baxter had his third relapse. Lenalidomide and dexamethasone had just been FDA approved to treat relapsed myeloma. Mr. Baxter did well with the lenalidomide for a few cycles, however, he continued to have sleep disturbance, he continued to have fatigue and anxiety, and he developed hand cramps, which can be a side effect of the lenalidomide.

He also developed cataracts, for which he had to have eye surgery. Cataracts can be a common problem with extended use of steroids such as dexamethasone. His wife also complained that he had fluctuating mood changes on top of everything else – agitation and irritation. So the lenalidomide dose was lowered and the dexamethasone was stopped. We were afraid single agent lenalidomide wouldn't be enough to keep the myeloma under control so we added PO Cytoxan[®].

Mr. Baxter went into a partial remission with very stable disease. However, he started having frequent infections and persistent pancytopenia. Now we know that pancytopenia can be a result of lenalidomide. So we stopped the lenalidomide, waited for the pancytopenia to improve, but it didn't. It persisted. So we did a bone marrow biopsy and unfortunately Mr. Baxter had a secondary cancer. He was diagnosed with myelodysplastic syndrome.

Slide 40

Disease and Treatment History

So we sent him to a specialist for myelodysplastic syndrome, who said fortunately, at this time we can observe the MDS. But now we have a new focus, a secondary cancer on top of the myeloma. Our treatment options for the myeloma were limited because we couldn't use bone marrow suppressive therapy. We were also concerned that the MDS would take a turn and need to take precedence for treatment over the myeloma. You can imagine the anxiety.

Unfortunately, shortly after this, Mr. Baxter developed new right shoulder pain and new left hip pain. And we know with myeloma that when a patient presents with new bone pain, he has probably relapsed. Once again, Mr. Baxter had his fourth relapse. Now we offered him bortezomib and dexamethasone, knowing that the ANC and the platelets would probably be lowered, it would be a struggle to keep the treatment going, so we started with a reduced dose.

Slide 41

Disease and Treatment History

Unfortunately the reduced dose of velcade was not sufficient for keeping the disease under control. So we added Cytoxan and Doxil[®] to the Velcade[®] and dex, but Mr. Baxter's immune system was so suppressed that he got pneumonia. We didn't even get to finish the first cycle of treatment. While Mr. Baxter was recovering from the pneumonia, we couldn't give him any treatment. So his disease continued to progress.

With bone marrow suppression, severely progressive disease, an immune compromised system, we had little else to offer Mr. Baxter. We told him this, but he said he wasn't ready to let go. He asked that we give him thalidomide and dex. We told him thal/dex would not work, but he insisted on having it. So one last time, we let Mr. Baxter have control. We honored his request. We gave him the thalidomide and dexamethasone.

Slide 42

Key Issues

You can see that there's an interwoven pattern of reoccurring side effects and long-term survival issues. Preexisting symptoms of anxiety and depression, exacerbated by the disease, causing sleep disturbances, which caused fatigue; fatigue which was exacerbated by the disease; bone pain and peripheral neuropathy from the disease and the treatments, which exacerbated the fatigue. It all spins together and creates an ongoing cycle.

There were also significant repercussions from the primary treatment which compromised Mr. Baxter's long term quality of life - sexual dysfunction, cataracts, osteonecrosis of the jaw (from the bisphosphonates), and MDS, a secondary cancer. Mr. Baxter's life was turned upside down and inside out physically, psychologically and emotionally.

Slide 43

Nursing Interventions

So what's a nurse to do? I knew I wouldn't get anywhere with this man without building trust. He was used to doing it himself, relying on himself and being in charge. He needed lots of reassurance and support. He needed consistency. Inconsistency would have caused distrust. So I first involved Mr. Baxter in his plan of care.

You've heard of the wedding planner. At my institution, I'm called the myeloma planner. Give me your cruise dates, your wedding dates, baptism and graduation dates. I will work your plan of care around the event.

Second, I tried to alleviate some anxiety by eliminating some fear of the unknown.

We offered Mr. Baxter education and resources, for which there is so much out there. Education with pamphlets, booklets, websites, phone numbers, and resources like The Leukemia & Lymphoma Society who have support groups, financial support, transportation, and on and on.

Third, I involved the team to offer Mr. Baxter optimal care and attention. Nurses don't need to do it all themselves. Point your patient in the right direction. Social workers can be a veritable wealth of help. And medications, there's medications for everything. Depression, anxiety, sleeplessness, peripheral neuropathy. All we can do is offer and hope that the patients will take what will best help them.

So the goal was to maintain a nonjudgmental, caring approach. Did I like this patient? Do we like all of our patients? He was directive, controlling, type A personality, rapid, repetitious, pressured speech, (it was difficult for us to get a word in) dismissive of the healthcare team's advice and recommendations. And then he would ask, "Why did everything go wrong?"

Slide 44

RN Experience

Eric Cohen:

So Kathy just asked a very honest question in front of about a thousand people. Do I like this patient? How many of us have patients that we just don't really like? And today, I hope to give you a little bit of a framework for looking at some of these more difficult patients, by adjusting the lens through which we view these patients.

Slide 45

Adjusting the Lens Through Which We View Our Patients

Why did this patient stop all treatment when we wanted him to continue? Why did he want to continue treatment when we wanted him to stop? Is there another explanation for his anxiety and sleep disturbances? What do we do with these patients that defy us at every turn?

Slide 46

Recognizing the Trauma in Our Patients' Lives

So I think the first thing is that we have to really look at our patients and find out and see them for who they are in this particular situation. We all have different faces. The faces of Kevin Bacon. And we all act different ways in different situations. So by looking at our patients and listening to them and letting them tell their story, I think we can get an idea of who they are with this disease and who Mr. Baxter was when he was diagnosed.

Slide 47

Needs of the Individual Living with Cancer

So one of the things that I think we don't talk enough about is the idea that our patients are suffering from trauma. Before I actually talk about trauma, I just want to show you this slide, which is all the needs that a cancer patient has. We are, as nurses, trained in the physical side and

the informational side, and today I really want to talk about the emotional and the spiritual side.

Slide 48

Trauma

So Mr. Baxter I believe was suffering from post-traumatic stress disorder and I think he absolutely had a trauma. But what is the definition of trauma? And I love this definition. It says a psychologically seismic event that can severely shake, threaten or reduce to rubble many of the structures that have guided our understanding, our decision-making and meaningfulness.

Slide 49

Japan 2011

This I think is what we normally think of when we think of trauma. This is a picture of Japan in 2011.

Slide 50

Post Traumatic Stress

But the definition for post-traumatic stress disorder, and this is from the diagnostic manual that mental health providers use, says that a traumatic event is any event where a person has experienced or been confronted with threatened death. So isn't that what our cancer patients are going through? Not only that, they also have to have experienced intense fear and helplessness.

Slide 51

Symptoms of PTSD

Some of the symptoms of post-traumatic stress disorder are involved with avoiding stimuli that remind us of what happened or the traumatic event. So that day of diagnosis. We want to do everything we can to avoid that, right? So we avoid activities or places or taking our medications or wanting to go to the doctor's office to get that fourth round of treatment, like Mr. Baxter.

The other thing is that they are also experiencing a lot of estrangement from other people. And I don't think Kathy mentioned it, but Mr. Baxter had a lot of estrangement issues with his kids, with his family.

The other things that she mentioned, and they're right here, difficulty falling or staying asleep, being irritable, difficulty concentrating. These are all symptoms of post-traumatic stress disorder.

Slide 52

Anxiety Management During Survivorship

So what can we do about that? I just want to say, though, that not all of our patients I think suffer from post-traumatic stress disorder. But I think there are some patients, many patients, that do. And it's those patients that I think a lot of times present to us as being those difficult patients.

So what can we do about their post-traumatic stress? First thing is looking at their anxiety and were they anxious before treatment and if they were anxious before treatment, we're probably not going to get them back to their baseline. I mean, back to having no anxiety. But hopefully we'll get them back to their baseline. Doing a deliberative assessment, what is worrying me the most right now, what is the biggest concern that you have right now, and then is there something

that we can do about that concern. And this is a lot of times where I have that conversation on control. There are things that we can control and there are things that we can't control. And let us try to focus and frame for you some of the things that you can control like stress reduction or diet and exercise, as opposed to are these meds working, is my cancer going away, what is this disease doing to my body.

We also have to rule out if there's a physiologic basis for anxiety. So are they suffering from opioid withdrawal, are they having dyspnea, are they having a lot of pain that would cause them to be extremely anxious.

We know now that they're not suffering from physiologic things that are impacting their anxiety, this is probably coming from their post-traumatic stress. So what are the things we can do that are really simple at the bedside, in the office, where we actually don't have to refer them out necessarily. So relaxation techniques. Just teaching them very simply how to breathe, taking nice deep slow breaths. Giving them a little imagery to think about, having them close their eyes and think about a safe place or a comforting place. And let's not forget about physical contact. Just reaching out and holding their hand or putting your hand on their forearm or wrist, really can melt away a person's anxiety. You can see a visual reduction in their anxiety.

We also have to look at how they want to receive information and how much information they want. So are they someone that wants every little detail, they need to know everything that's going to happen in order. Or are they just people that want the big picture. So figuring that out and then delivering the information to them, in the way that they can hear it.

Also I hear a lot of times that physicians, when they're talking about what's going to happen, they give them very short or very little blocks of what might happen. So at diagnosis, they'll talk just about the induction or the consolidation period, and they don't really want to talk about what they're going to do in maintenance or beyond. This can create a lot of anxiety for patients, not knowing what's coming up or what's going to be the next thing that we do. And so by just entertaining that with them and exploring a little bit and giving them some ideas about what maintenance is going to look like for them or what beyond survivorship is going to look like for them, can be actually very helpful for some people.

Slide 53

Distress Management

This is a great little tool, distress management tool, distress thermometer. I'm sure we'll hear tons about this tomorrow at the Mara lecture, as Betty Farrell will be presenting. But this is a great little tool to sort of assess where they are and a little checklist that gives you an idea of what are some of the things that are on their mind that you can address with them.

Slide 54

Recurrence Anxiety

So the idea of recurrence creates a tremendous amount of distress in people. So much so that it really does impact their attitude and their mood and their behavior. Every little twinge of pain or a cough that seemingly isn't going away is a reminder for them that maybe that's the cancer coming back.

Slide 55

No title

So much so that when the angel of death comes, he says don't panic, I'm just a sore throat.

Slide 56

Potential Corollaries of Recurrence Anxiety

I co-facilitate a lot of support groups. And this slide really illustrates all of the things that I hear in my support groups on a regular basis. So the Damocles syndrome. That is that Damocles was a Greek mortal who was invited by the king to sit at the king's table and partake in this beautiful feast, feast of food and wine and just an incredible table that was set for him. But what the king did was he placed a sword right above Damocles' head and at any moment that sword could fall and plunge through his heart. And isn't that what our cancer survivors say all the time? I'm so thankful that I made it, that I'm here, but I'm worried that it won't last very long, that at any moment that sword could plunge.

Emotional immobilization, that idea of being stuck, of feeling numb, of not being able to experience a joy. This is something that also creates a lot of anxiety in people. Using denial, symptom minimization, sometimes that is something that also they'll say is causing them a lot of anxiety actually when we explore it.

The idea of anxious preoccupation. So that every little twinge of pain or that cough that doesn't go away, and needing to know exactly what that is.

A lot of people complain of having these opposing feelings about their surveillance, what we should do in the future, and that idea that every three months they've got to go back and get scanned or get another test, creates just tremendous anxiety. And I've got to tell you if I were a cancer survivor, I don't know how many times I could go through that. I'm okay, I want the information, I want to know if my cancer is in remission, but at the same time that week before the scan or the test, I don't want to go back. And how many times can you do that? I think can really wear on people.

Conversational isolationism/disclosure isolationism. So now as a cancer survivor you feel good, or you feel better, and you look well and you're going out in public now and people, you don't know if they know, how much do they know, what do they know, who knows, who told who. And so you're always sort of feeling like God, I don't know if I should say anything, it's a big part of my life, but at the same time I don't want to tell everybody, and that also can create a lot of anxiety.

Limiting plans for the future. Not being able to sort of plan for vacations, not knowing what is just around the bend.

And this recurrence anxiety is really the most intense about a year or two from finishing treatment. So they have now finished treatment, for a year they feel pretty good, they feel great, and then all of a sudden it starts to hit, oh, my God, what just happened to me, even though it was a year ago or two years ago. And it is extremely anxiety-producing.

Slide 57

Fluctuating Mood: Depression

Cancer is also all about loss. So this loss leads to more depression. Loss of a sense of self as being a well person. Loss of control. Loss of what your life was supposed to be like. Loss of independence, of future life events, I'm not going to be able to have kids any more or maybe I

won't see my child's wedding. Loss of financial security. Mr. Baxter losing his job or not being able to go back to work. And loss of what your usual work is and your usual role. So at work I was the boss and now I can't really be the boss any more. Or at home I was the husband or I was the bill payer and now you're not really able to do that. And so again, another demoralizing idea.

And a lot of times, loss of established social support. So friends who just can't deal, they can't hang, so they just start to disappear.

Slide 58

Depression Spectrum

I wanted you to see that depression really is a range, a spectrum. That there is normal sadness, that just because somebody is a little tearful or is crying at the moment doesn't make them candidates for medication. There's a whole range of before we actually need maybe to get them help. But certainly we don't want to dismiss it either. But normal sadness is something that I think we see a lot. I get calls a lot of times, oh, Mrs. So and So is crying, can you come see her. Is it she just can't stop crying or is it she's just feeling a little down today?

Slide 59

Can Patients Like This Ever Get Better?

So can patients like Mr. Baxter or other patients or patients that we find difficult, can they actually get better? Yes, I think absolutely they can get better. Cancer leads us, is that major traumatic event, immediately into a struggle. And if we can sort of stick with our patients in that struggle and recognize their struggle and listen to their story, we can help facilitate getting them back to that place of growth, getting them into growth. Isn't that what Charlie sort of was talking about yesterday in the opening ceremony? He said, "can't go back, I'm somebody new." So that that struggle made him a different person. It's not the cancer that caused him to change, it was that struggle that he went through that brought him to that place of growth.

And not only the patient getting to a place of growth, but I think the nurse, us as well, as a professional caregiver, if we can stay with it and get through that struggle with the patient, as difficult as it may be, we get to a place of growth as well.

Slide 60

Eric's Summary

This is a quote by Victor Frankl, who was a Holocaust survivor, a cancer survivor, a neurologist and a psychiatrist, and his book, *Man's Search for Meaning*, he says, "when we are no longer able to change a situation, such as cancer, we are challenged to change ourselves."

And I just want to leave that with Kathy.

Slide 61

Kathy's Summary

Kathy Daily:

So over time and through acceptance, I did see beyond the challenges of the behaviors of this patient. So fortunately for him he didn't have to change. I changed. Thank you.

Clare Karten:

Kathy and Eric, thank you for painting such a vivid picture of the human side of what you all do.

Slide 62

Question and Answer Session

Now we come to the very important interactive part of today's symposium. Your questions and comments are very valuable.

I hope you won't mind if I ask one question, which is Kate and Carol and Eric and Kathy, if you'd like to comment, too, in listening to the first case today I was wondering if it arises in your work that, if you want to move to strictly a palliative care setting and you see that as advantageous for the patient, but you're working with physicians who want to continue with the therapeutic approach as well. Does that ever come up?

Kate Breitenbach:

That comes up all the time with Carol and I. Some of the physicians that we work with are really true researchers and so sometimes when patients have had multiple relapses, they still want to kind of approach the patient to go on a clinical trial and receive a little bit more therapy. Which Carol and I don't always agree with. And I can think of a specific gentleman that I knew who had FLT-3 mutated AML and he had gone through front-line chemotherapy on a clinical trial, relapsed, ended up going to stem cell transplant, relapsed after that, was on another clinical trial and relapsed again. And our physician was away and out of town and so it kind of fell to me to go upstairs and have the conversation with the patient about changing goals of care. And I know that the patient was very surprised with a lot of what I had to say, which made the conversation even more difficult, but really talking about all the different options. And I guess how I approach it, which Carol can comment how she might approach something like this, but when I approach it I always say you know, there are certain patients who may want to continue fighting and do everything, even knowing that getting another treatment might not be the most beneficial for them. And there are other people who think a little bit differently and want to do more of a palliative care approach or do something that's just supporting their symptoms, so that they can go home and be with their family and do some of the things that are most important to us in our lives.

And it was really frustrating for me to have put all of these pieces into place for the patient to go home with what I thought was a good deck: getting palliative care nursing and hospice nursing in the home for the patient, and then to have the physician kind of question what my motives were and why I was doing something like this.

And I know I talked with Carol about this patient and physician that we work with and how frustrated I was, that I'd bent over backwards for this person and the physician just kind of said well, I'm not interested in what we can't do for his leukemia. And Carol told me I should have said something at that point and I wish I would have because I think letting the physician know I have worked so hard for this patient and this is what his wishes are, and I wish that you would respect that, too.

Carol White:

I think sometimes, too, being a research center, that oftentimes, just like our case study

patient, Ron, patients come to us for second opinions or for the clinical trials because they don't want to give up. And I don't think it's necessarily incorrect to offer patients, young, old, middle aged, a clinical trial. I think that that's how we learn, from research, and might be a benefit to the patient. But I think we do need to, along with that, give them the option of palliative care. Introduce early on that the chances for a cure or a remission are slim with standard of care treatment. And I know our physician, each time Ron came to the office and was ready to start another treatment, asked them how their quality of life was and asked them did they want to continue with this aggressive treatment. So I think it's a question that we don't have any answers for you. Could probably spend the next five hours debating this issue.

Clare Karten:

Thank you. It's kind of hard for me to see, are there any other questions? Can you just go over to the mic so everybody can hear you?

Audience:

I work in hospice and home care and when my mother-in-law actually had lymphoma, we had the same difficulty of transitioning her from care to palliative. I've been seeing some projects out there for concurrent care, because I think one of the main problems is getting Medicare to pay for palliative care. Are you familiar with concurrent care? I think there are some projects that are out there now, where it allows hospice with still some treatments, because it really for me, seeing her get treated with Rituxan, really did a lot to relieve the pain that she was having.

Carol White:

I don't think there's any concurrent care with hospice and active treatment and payment, but with palliative care there is, in many situations. But with hospice...

Audience:

Oh, with inpatient? In a home care it's difficult. Thank you.

Clare Karten:

We have another question over there.

Audience:

With Mr. Baxter, do you think introducing spirituality would have been a helpful alternative to helping him accept some of the things that you want to help him with?

Kathy Daily:

That's a really good question. I wondered if anyone would notice that that wasn't in there. Because he indicated to me over the years—you know how patients give off their cues in the things that they say—that this wasn't really a part of his life. Even up until the end, he was just desperate not to die, indicating to me that he didn't have any thoughts of an afterlife.

Eric Cohen:

I think if patients express an idea of spirituality, then absolutely. But in his case he really

wasn't going there it seems. And so I don't think that would have been helpful to do that. I think he would have completely dismissed it. And in fact, I think it probably would have impacted the trust that he had with Kathy if she had started to move in that direction. Because he just did not want to go there.

Kathy Daily:

Thank you, though. I wondered if anybody would notice that. So thank you very much. That was a really good question.

Audience:

On the myeloma case study it said the patient developed osteonecrosis of the jaw. Zoledronate stopped. Is that like a frequent side effect?

Kathy Daily:

Yes, I'm sorry, that's Zometa[®], it's a bisphosphonate. And osteonecrosis of the jaw is a side effect that can occur with any bisphosphonate. Once that happens the patient should no longer have bisphosphonates ever. So there he lacked more support in strengthening his bones, which is a big part of his disease.

Slide 63

Thank You

Clare Karten:

I wish we did have some more time, but I want to thank you all for participating. And we hope that the information presented today will be useful to you in your very important work with patients and families.

Please stay in touch with us at The Leukemia & Lymphoma Society.

Thank you.

END