Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson, I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address iscanceranswers@yale.eduand the phone number is 1888-234-4YCC. This week, Francine is pleased to welcome Dr. Melissa Carlson. Dr. Carlson is Assistant Professor of Geriatrics and Palliative Medicine at the Mount Sinai School of Medicine and she joins us for a conversation about hospice care. Here is Francine Foss. Foss Let's start off by having you describe the word hospice, what does it mean? Carlson Hospice care is an interdisciplinary approach to care for patients who are suffering from serious illness, and by interdisciplinary, I mean it includes medical care such as pain and symptom management, but it also includes counseling, so spiritual counseling provided by chaplains, nutritional counseling as well as support and services for a patient's caregiver, things like respite care and bereavement counseling. What many people do not realize about hospice care, is it is primarily home care, so services and individuals go to the patient's home to provide the care. Foss Can you tell us a little bit about how you became interested in this field and a little bit about what your background is? Carlson I became interested in the field of palliative care as a graduate student here at Yale School of Public Health. I worked with Dr. Elizabeth Bradley who is in the School of Public Health, and what we were mostly interested in was the dramatic growth and change that we saw in hospice care, for example, there were roughly 2000 hospices in the US in the early 90s, whereas today there are about 4800. Where hospice care started out as a non-profit service where the agencies tended to be small, today, about 50% of hospices are for profit owned and about a quarter serve more than 500 patients per year. So what I became interested in was how that growth and change in the hospice industry translated into quality and access for patients and families in the US. Foss Can you describe hospice care to those that might not be familiar with it, what exactly happens when a patient signs on with hospice? Carlson Hospice care in the US is covered by Medicare hospice benefits and that dictates certain eligibility criteria for enrolling with hospice. Specifically, an individual must be considered to be terminal, meaning they have six months or less to live as certified by a physician, and they also must forego reimbursement for curative care that is focused on curing their underlying terminal illness. Once those criteria are met, they are referred to hospice by their oncologists or their primary physicians and then they receive the interdisciplinary, fairly comprehensive, care that I previously described. 3:18 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3Foss In terms of who is offered hospice care, it is mostly a patient who is considered to be terminally ill? Carlson Yes. Foss Is that six-month period a magic number, how does one know that one has six months to live? Carlson It is very difficult and that is one of the

concerns about these eligibility criteria as prognostication is incredibly difficult, particularly for certain types of diseases, and what we see is that although there is increasing use of hospice in the US, more than a million patients right now each year receive hospice care, many receive hospice care for only a week or less and that is because it is very difficult to determine that a patient is in fact terminal until the very end stages of illness. Foss A lot of patients are afraid of the word hospice because they think about somebody coming with a syringe of narcotics or something and putting them to sleep, or that it is kind of a final act, could you talk a little bit about how you get over a patient's fear of hospice and how the whole hospice concept has been changing? Carlson I think we need to make a more engaged effort to discuss what hospice care is and what palliative care is and I think that hospice care needs to be part of an ongoing discussion with patients and families about their goals of care and preferences for care. Ideally, the discussions about palliative care can start really at the time of diagnosis of cancer or another serious illness and can be received in conjunction with curative care, so that the discussion of hospice becomes a more natural progression once the individual does not want to continue curative care or when that curative care is not meeting their objectives. I think a more ongoing fluid dialogue that starts with palliative care at the time of diagnosis would facilitate the transition into hospice and really educate patients and families in a much better way. Foss Some people have said that hospice actually improves the quality of life for patients who do not have that much longer to live for a lot of different reasons, how do you feel about that? Carlson I think the evidence is there that patients have benefited in terms of quality of care and satisfaction, improved symptom control and the ability to be home in those final stages of illness and some other work that we have done looked at patients having fewer hospitalizations and a higher likelihood of home death if they are able to stay in hospice from the time they enroll until their period of death. I think the benefits have certainly been shown through research. Foss The whole hospice decision often times involves not only the patient, but also the patient's family as well, how do you integrate everybody into that picture? 6:22 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3Carlson You integrate everybody into the picture through the team approach, many of the individuals who might come to a patient's home, are really there to serve the caregiver. The benefits of those services for the caregiver start at the time of hospice enrollment and actually continue for up to a year after the patient's death. If you are at a hospice center that has really embraced that full interdisciplinary team approach, those services will be there for both the patient and for the family, and we have also seen a number of benefits that have been shown to the family in terms of better bereavement adjustments and greater satisfaction with the patient's care having hospice involved. Foss Can you talk about how the patient actually interfaces with hospice? Say a patient is being seen in the oncology clinic and they have their caregivers at the hospital and in the clinic, how does one make the transition to hospice and how is the patient introduced

to hospice? Carlson Generally, the patient is introduced through their oncologist. The oncologist would make the referral based on ongoing discussions about what their goals are, and if the patient and family do not want to go for another round of treatment and they say what are my options, many times the discussion might be initiated by the patient and family, but most often it is initiated by the oncologist who then would refer them to a local hospice agency where they would meet and get together a plan of care to transition the patient home. Foss These hospices are not part of the hospital, they are free standing? Carlson About 60% of hospices in the US are free standing, another 20% are affiliated with a hospital and another 20% are affiliated with a home health agency. It depends on the area that you are in. Foss Is it possible that a patient would actually have more than one hospice option available to them? Carlson In some cases, yes. Some of the recent work that we have done that was published in The Journal of Palliative Medicine found that although 98% of the population in the US lives within an hour of at least 1 hospice agency, only about 60% live within an hour of 2 or more hospice agencies. Most people will have at least 1, so geographic access to care is there, but many will not have a choice between multiple providers. Foss Can you talk a little bit about the age of the patients that you see in hospice, is this something open to very young people as well as older people? Carlson Because of our reimbursement, because it is primarily reimbursed through Medicare, about 85% of hospice patients are age 65 or older; however, any age could be appropriate for hospice depending on their eligibility, their goals and preferences for care. There is a growing area of research and outreach in developing pediatric hospice care programs, particularly for children with cancer; 9:31 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3however, at this point that still represents only about 1% or 2% of all hospice care. Foss Can you talk about what types of cancers or what types of diseases, I should say, are the most common in the hospice setting? Carlson Initially hospice care was directed towards patients with cancer, and even in the early 90s, we saw that upwards of 80% to 90% of patients had a diagnosis of cancer. At this point, patients with cancer represent about 40% of hospice patients, so still the single largest diagnostic group, and within that about a quarter of patients have lung cancer and then the next highest are colon cancer and prostate cancer. Foss Can you talk a little bit then about individual patients? For example, at what point a patient may want to go to hospice, I can understand that in some situations the patient may have decided that they have had enough treatment, in other cases, the physician may have told them that there is no further treatment, so do you see both of those groups of patients coming into hospice and do you handle them any differently? Carlson Yes, both types of patients are in hospice. We do not have any data on precisely what percentage are patient initiated versus physician initiated. It is usually a team approach, it is usually multiple discussions, and sometimes the family actually is the one who brings up the idea of hospice care, primarily because an individual wants to get back

home. We know the people want to be out of the hospital or out of some type of inpatient facility, but the patient as well as the family feels that they need much more support to have someone with such a serious illness in the home setting, so it really comes from all angles; the patient, family and the physician, and once all are on board, you can really get a team together. Foss If a patient has a lot of medical issues, as many of our cancer patients do, do you interface and work with the visiting nurses while you are in the home as well? Carlson It depends on the setting, again many hospices have different connections with the community to the extent that there is a visiting nurse already set up or already affiliated with the hospice, that can happen but it differs in each market. Foss In Connecticut, we have inpatient hospice as well as outpatient, can you talk a little about the differences between the two? Carlson About a quarter of the hospice care that is provided in the country is provided in an inpatient hospital facility, although that is really for individuals who have perhaps multiple comorbid illnesses, and really extensive medical needs in terms of pain and symptom management, and often 12: 21 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3it is people who do not have a caregiver in the home setting, so although hospital care can be provided in the home and the team will come to the home, there really needs to be an active caregiver there as well to provide some of the supportive care in the intervening periods. So, the inpatient care then tends to be a higher level of hospice care that is used either after the home care is not working effectively or just in the case of a person with multiple comorbid illness. Foss That points me to the next question, and I think we have touched on this a little bit, but could you just talk a little bit more about the benefits of receiving hospice care, the benefits for the patient, and then the benefits for the family as a whole? Carlson What we found is for patients there is generally a perceived higher quality of care for those who are receiving hospice, greater satisfaction with care, and potentially improved symptom control, as well as for the family, there is greater satisfaction and family support and one of the things that we looked into more detail is the issue of hospice disenrollment, so people who were on hospice for a period of time and then actually disenroll from hospice, and what we found is that during the period that they disenrolled, they were far more likely to be hospitalized, and that is in the ER, the ICU, and far more likely to experience a hospital death. For many people who have chosen hospice and then go off hospice, you can have much higher rates of some of these outcomes that people had said that they do not want at the end of life. Foss I would like to talk a little bit more about your specific research in this area when we come back from this short break for our medical minute. Please stay tuned to learn more about hospice care with Dr. Melissa Carlson. MedicalMinute This year over 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone there will be over 2000 new cases. More than 85% of lung cancer diagnoses are related to smoking and quitting, even after decades of use, can significantly reduce your risk of developing lung cancer. Each day patients with lung cancer are surviving.

Thanks to increased access to advanced therapies and specialized care new treatment options and surgical techniquesare giving lung cancer survivors more help than they have ever had before. Clinical trials are currently underway at federallydesignated comprehensive cancer centers like the one at Yale to test innovative new treatments for lung cancer. An option for lung cancer patients in need of surgery at Yale Cancer Center is a video-assisted thoracoscopic surgery, also known as a VATS procedure, which is a minimally invasive technique. This has been a medical minute. More information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network. Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined today 15:22 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3by my guest Dr. Melissa Carlson, and we are talking about hospice care. Melissa, before thebreak, you mentioned a study that you had done looking at disenrollment from hospice programs, can you talk about what disenrollment is and then can you talk a little bit about your study? Carlson Yes, thank you, we recently completed a study where we looked at over 90,000 individuals with cancer in the US who had used hospice prior to death and what we found was that roughly 11% of those individuals disenrolled from hospice prior to death. The idea of hospice is that you enroll as an individual with a terminal illness who wants to be at home with supportive care and the services are continuous all the way until the patient's death and for a year after where the caregiver can continue to receive supportive services; however, about 11% disenroll prior to death, which is concerning in terms of continuity of care, and what we found is for this group who disenrolled, they were much more likely to end up in the hospital. For example, about 34% of those who disenrolled went to the ER at some point following disenrollment, compared with only 3% of individuals who remained on hospice until death. Similarly, about 10% of those who disenroll experience death in the hospital versus 0.2% of those who stay with hospice until death, so there is a much higher rate of hospitalization, which most patients say that they actually want to avoid at the end of life. In a study looking at higher rates of disenrollment, we also found higher rates of hospitalization following disenrollment that translates into much higher expenditures, and so the other aspect of the study, in addition to finding perhaps poor quality outcomes for this group of patients with cancer, we also found much higher Medicare expenditures due to their higher rates of hospitalization. Foss Do we have any idea why these patients disenrolled? Carlson That is difficult to say, and we cannot tell from this data exactly why they disenrolled. Disenrollment can be initiated by the patients, they can perhaps enroll with hospice and not have had a clear understanding of what hospice involved or the fact that they needed to forego curative care and they can then disenroll. It can also be because of variation in quality. Some of our previous work has actually tried to look across hospices in the US and understand if they are all providing the same interdisciplinary, full comprehensive package of care, and in fact, they are not, there is quite a bit of variation across hospices and what we are seeing

in terms of the services they provide, so it could be a quality issue as well. Hospices themselves can also initiate a disenrollment if they do not believe the patient is terminal anymore, if the patient moves out of the service area of the hospice, or if it is too complex of care for that hospice to provide, so there are many reasons and we were not able to differentiate those reasons within the study, but that is in area that would be important for feature research based on what we found. Foss Melissa, you said that 34% of the patients were re-hospitalized, do we know whether there was anyimpact on the overall survival in those patients versus the ones who are managed at home? 19:02 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3 Carlson We can't tell overall survival differences based on the way that the data is collected, but one thing that we can tell is that most of the people who disenrolled it is not that they actually became better and were not perceived to be terminal, because the average number of days between disenrollment and death is 24, so within three weeks most of these individuals had passed away, so the higher utilization is just impacting their quality of life in those final weeks of life. Foss And also that two or three weeks really did not make any difference in the outcome, so I guess from an expenditure point of view one could question that? Carlson Yes, exactly. Foss The other major issue that you brought up and we did not touch on was the issue of whether or not there are standards of care, or just plain standards across all hospice programs, so that is one question, and the second question is to what degree is the Medicare system involved in establishing those standards? Carlson That is a great question and this relates to some new research that we are working on. In 2006, the National Quality Forum adopted what they have called the preferred practices for hospice and palliative care, so these are evidence based practices that you would like to see across the industry, palliative care and hospice care, and so one of the things that we have done is to actually survey hospices. We have worked on what we call the national hospice survey with Dr. Bradley and other colleagues at Yale School of Public Health and Mount Sinai, and we wanted to understand the extent to which there was variation in the implementation of these preferred practices. What percent of hospices had implemented the preferred practices and how did it vary across hospice types, so hospices that were for profit versus non-profit, hospices that were larger or smaller? This was really our first look at how quality standards might vary across hospices because we have very little national data on that right now. CMS currently reimburses for hospice care on a daily basis with little information about what they are reimbursing for. I think it is critical to really dig down deeper and understand how the package of services might vary across hospices at this point. Foss Are there inspections of hospices like we get inspections at the hospital level for quality of care, are there inspections that are ongoing for various hospice programs? Carlson Hospices need to satisfy what are called conditions of participation to actually receive reimbursement from Medicare, so there are certain standards in terms of staffing, in terms of the percent of home versus inpatient care days, different

criteria along those lines that hospices are held accountable for, but they are not very detailed, and as of yet, they do not relate specifically to 22:13 into mp3 file http://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3 some of the quality or preferred practice measures that are still evolving within the palliative care field. Foss If one wants to know whether the hospice that they are engaged with is using the preferred practices, is there any way to get that information, say, as a consumer? Carlson At this point, there is not. It is one of the things that is being discussed more, what types of measures do we want reported for hospices so that patients and families can access that information before they choose hospice, but at this point that information is not actually out there. Foss Can you talk a little bit about the impact of your study? Your study was published in a very high profile journal, The Journal of Clinical Oncology, and I am sure that there has been some controversy about the study, so if you could talk a little bit about what you feel the impact of this study has been in terms of changing what we're doing? Carlson There was quite a bit of interest about the study. There are two aspects of the study and the fact that they came together here gave this a high impact. First of all, on the quality side, we want to look at what happens to people when they disenroll and what happens to people who aren't on hospice, and the fact that there are higher rates of hospitalization is not surprising for many people who practice in the field, but what we need in palliative care are more studies to build the evidence base to show that this is a high quality service that benefits patients and families, but on the policy side, what we also need to show is that hospice care can actually save money. There are a few studies already starting to show this, although it can be difficult methodologically to do, but to show that through perhaps more expanded coverage of hospice care and aligning what patients want in terms of preferences for care with what they actually receive, there is a potential to save Medicare money. I think in order to get additional reimbursement for palliative care more broadly, or hospice care, as well as more funding for this type of research, we need to have the studies that actually show what some of the benefits are, both in terms of quality and in terms of finances. Foss There is obviously the conflict, or the collaboration, however you want to look at it, between the policy side and the medical side, can you talk a little bit about where hospices are in that whole process and how you think some of the upcoming proposed health care legislation may affect where hospices are going in the future? Carlson Other things that people are concerned about with hospice care specifically are some of the eligibility criteria, and why more people are enrolling in hospice. Many people feel, and some studies have shown, that it is difficult to prognosticate and even more controversial, the idea that one needs to forego curative care in order to receive hospice care. It is not the continuum that 25:22 into mp3 filehttp://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3you'd like to see, but more of a break so one of the things that has come up in the recent health care legislation is funding for some demonstration projects, and those projects will actually allow people to receive simultaneous

curative care with hospice care, and what these demonstration projects will track are quality outcomes, clinical outcomes, as well as some other financial outcomes. So, is starting hospice care earlier in conjunction with curative care going to save money down the road, and then what are the exact impacts for patients and families on a quality and clinical side? Some of that, I think, will provide additional evidence and perhaps change some of the ways that we reimburse for hospice care, if those eligibility criteria are modified based on some of the demonstration projects. Foss I think that is really important because many patients, and I have certainly had patients in this situation, would like to benefit from what hospice offers to them, but they are still taking some form of treatment, or getting IV fluid, or doing something to support their disease and their treatment, and that often times is a rate-limiting step for the hospice engagement. Carlson Yes, it is, and again, a distinction between palliative care and hospice care is the timing, so palliative care is the same set of comprehensive services, but it can be initiated at the time of diagnosis, and when we see that studies are showing much better outcomes in terms of satisfaction, and even length of life and financial outcomes when that is initiated early, the potential for hospice then to be started in a way that is more continuous as opposed to abrupt is also there, so in both areas, palliative care and hospice care, there is a potential to get more evidence to really see some of those benefits. Foss What do you think the benefit would be to the patients say if hospice were engaged at the very beginning? Say a patient who we know has terminal lung cancer, should hospice get involved at the very beginning of that treatment plan or should hospice get involved later on? Carlson While hospice care can't get involved until the eligibility criteria are met, if a palliative care team at a hospital, say an inpatient or an outpatient palliative care team is involved, the tremendous benefit of getting those discussions started early on has been shown in terms of aligning what that patient wants to do with how that care is then carried out, and so then that can facilitate getting hospice involved at the earliest point if that is appropriate. Not within two or three days of death, but maybe more towards three, four, or five weeks prior to a patient's death. Foss I think that what you last said is a very very important point, as a practicing oncologist it is very difficult when you are in those last few days or even weeks and you are scrambling to try to get hospice involved at that point when there are so many other issues that need to be addressed. Carlson Yes, exactly, and the growth of palliative care programs in hospitals is a testament to that, getting 28:55 into mp3 filehttp://www.yalecancercenter.org/podcast/may2911-cancer-answers-carlson.mp3those conversations started, increasing education and awareness, so it is not in a crisis moment that you are bringing up some of these discussions. Dr. Melissa Carlson is Assistant Professor of Geriatrics and Palliative Medicine at the Mount Sinai School of Medicine. If you have questions or would like to share your comments, visityalecancercenter.org, where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.